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Sarah Franklin and Celia Roberts, 'Innovative Health Technologies: The Social Life of the Embryo', published by the Department of Sociology, Lancaster University, Lancaster LA1 4YN, UK, at <http://www.comp.lancs.ac.uk/sociology/papers/Franklin-Roberts-Social-Life-of-Embryo.pdf>

Publication Details

This web page was last revised on 28th November 2003; the paper was previously published at <http://comp.lancs.ac.uk/sociology/IHT/eofcpaper.htm> in 2001

Innovative Health Technologies: 'The Social Life of the Embryo'

Sarah Franklin & Celia Roberts

Paper presented at 'Ethnographies of the Centre,' Lancaster University, Lancaster, 10/9/01

Introductory note on method

Our experimental project looks for repetitions in the representations of the various participants in our study – in terms of what people understand by genetic information, how they describe the technique of genetic diagnosis we are studying, and, for the purposes of this paper, how they describe embryos.

Our method – which we call 'ethnpoint' - involves collecting these repetitions, and presenting them back to project participants in a very formalised way, using the facilities of powerpoint to present layers of quotations, both written and aural. We then record responses to these representations, listening for points of both recognition and misrecognition. Our aim in this is both to produce a set of conversations and exchanges, and to analyse them systematically, so that our ethnography is both 'for' our audiences, and yet also 'for' itself.

Introduction

Our current ethnographic project is part of the ESRC and MRC's 'Innovative Health Technologies' programme and has been running since February. We are working with two



clinics offering a new technique known as pre-implantation genetic diagnosis. One centre, at Leeds General Infirmary in the North East of the UK, is in the early stages of (re)developing its PGD programme, and has not treated any patients for over 18 months. The other centre, based at St Thomas' hospital in London, is one of the most successful and productive PGD clinics in the UK, and indeed the world. (There are currently only 6 centres licensed by the Human Fertilisation and Embryology Authority to offer PGD in the UK). St Thomas' treated 37 couples in the last financial year, and aims to increase this to 60 in the current year. They have had over 20 babies born as a result of PGD in the history of the clinic's operation.

As a multi-sited ethnography, the study ranges across a number of sites that constitute the worlds of PGD. These include: government and statutory regulating bodies (the HFEA, parliament, and the Department of Health); lobby groups (PROGRESS); patients (we are interviewing couples and individuals in their homes); scientific bodies (The Royal Society and the British Fertility Association); and the media. Our methods range from textual and visual analysis, through participant observation and in-depth unstructured interviewing.

For the purposes of this conference, we tried to think about ethnographic approaches to centres and peripheries, following Lucy Suchman's suggestion that we think critically about how centres, or central objects, get constituted, and what kinds of worlds are produced from defining centres in this way. We found this a very helpful exercise, particularly in relation to the embryo, which might easily be taken as the centre, or central object, of PGD. In traditional STS or ANT style, the embryo could easily be our 'guide', as it were, in a 'following the object' kind of exercise, and we have found it very helpful to explore in this paper what happens both when we centre the embryo, and when we look at what gets displaced by the embryo when it is positioned in this way. This paper is consequently divided into two parts: the embryo as centre, and decentering the embryo.

Embryo as centre

The embryo in the clinic - To begin we should tell you a little more about PGD. Obviously this is hard to do without slipping into ways of speaking that our project seeks to avoid – either by pinning down 'what PGD is', or reverting to more authoritative scientific accounts. However –

Pre-implantation genetic diagnosis is the first technique to bring together in vitro fertilisation with genetic testing, and is, in this sense, a further extension of the technique of IVF. Like PGD, IVF could be seen to be very orientated around the production of embryos – in particular getting enough 'high quality' embryos to transfer back or freeze for future use. The term 'pre-implantation genetic diagnosis' refers to a process of biopsying embryos by removing one of their cells, extracting its nucleus, and testing it for a specific genetic condition. PGD is a means of diagnosing embryos in order to determine which embryos are free from that disease (or are 'clear') to be transferred to women's uteruses, in the hope that they will grow and be born as babies who do not and will not suffer from the genetic condition that the embryo was tested for.

In one sense, then, PGD is about making embryos, taking pictures of embryos, screening embryos, selecting embryos, transferring embryos, and mostly hoping embryos will grow into babies. Embryos could easily be seen to be at the centre of PGD both as the most 'highly valued' objects in the clinic, and as intensive work objects as well.

The embryo, in sum, is a sociomaterial actor existing within a broad set of technical and social practices. Within particular technical scientific and biomedical practices – those of embryology, cytogenetics and assisted conception - under the microscope and within clinical discussions, it is literally centred as a sociotechnical object. Practices constituting the technoscientific and biomedical aspects of IVF - egg and sperm collection, ICSI (intracytoplasmic sperm injection), embryo culture, embryo freezing, and embryo transfer – are all focussed around the production and preservation of 'good' embryos. The embryo, it might almost seem, is everything.

The public embryo - But embryos are also central to PGD outside the clinic, for they are highly contested political objects, highly regulated legal objects, and increasingly are highly valuable commercial objects as well. Embryos are arguably increasingly important as visually



iconic objects, and they are undoubtedly seen as highly sacred objects, in particular by the Catholic church.

In Britain, embryos have been the subject of considerable public and parliamentary debate, culminating in the establishment in 1991 of the Human Fertilisation and Embryology Authority, which now licenses all research undertaken on human embryos in the UK (and has become the model for similar regulatory bodies in several other countries). Although embryo research is comparatively uncontroversial in Britain, it is the subject of intense controversy in other countries, and in particular in the US and Germany. Whereas German opposition to embryo research derives directly from the legacy of racial hygiene during WWII, US opposition is much more religiously based.

According to fundamentalist Christian interpretations, and Catholicism, life begins at conception, life is a gift from God, and the embryo is consequently sacred, as it embodies the divine gift of life. During his August visit to the Pope's this year, George W. Bush was advised to consider the embryo as *life* in his deliberations on the possibility of allowing federal funding of stem cell research. This visit is described by Victor Simpson of the Associated Press:

CASTEL GANDOLFO, Italy -- Pope John Paul II urged President Bush in their first meeting together to bar creation of human embryos for medical research, saying today that America has a moral responsibility to reject actions that "devalue and violate human life."

The 81-year-old pontiff and Bush met behind closed doors at the papal summer residence Castel Gandolfo in the foothills south of Rome.

John Paul, stooped and frail in his chair, afterward read a statement to Bush and his entourage.

The pope lamented:

"Experience is already showing how a tragic coarsening of consciences accompanies the assault on innocent human life in the world, leading to accommodation and acquiescence in the face of other related evils such as euthanasia, infanticide, and, most recently, proposals for the creation for research purposes of human embryos destined to destruction in the process."

"A free and virtuous society, which America aspires to be, must reject practices that devalue and violate human life at any stage from conception to natural death," the pope added.

Before their statements, Bush gave John Paul a book of poetry. They stood together on the balcony of the pope's library, overlooking the clear blue waters of Lake Albano, and Bush commented: "On a hot day it looks like a place one would go swimming."

George Bush has recently licensed 60 specified colonies of embryonic cells held by the University of Wisconsin for use in the US, but his decision has been widely interpreted to signal major economic disadvantages for US competitiveness in the biotech economy, as a new 'brain drain' of molecular biologists moves to countries such as Italy, where there are fewer restrictions.

Whilst Britain has not had as powerful a religious opposition to embryo research, the embryo has nonetheless been the object of considerable public concern, and has been at the centre of a number of parliamentary debates. The 1990 Warnock report, which established the framing approach to the embryo that is still followed in Britain, speaks, for example, of 'respect for the embryo' as a central value of scientific and medical endeavours.

As part of ongoing parliamentary debate concerning the use of stem cells, speakers from all parties and both houses of Parliament have spoken at length about the moral status of the human embryo. Parliamentary undersecretary of state for health Yvette Cooper stated during the stem cell debate that she is 'not aware of any statutory instrument that has received so much detailed scrutiny and debate on the Floor of the House. Indeed,' adding that, 'the staff of the Journal Office do not know of any statutory instrument in their memory that has been accorded so much consideration' (House of Commons, 19 Dec 2000, Column 209.)

Although there are profound disagreements about whether embryos should be used in scientific research in these debates, a focus on the unique importance of the embryo is



shared. Mr Gareth R. Thomas, MP of Harrow, West, commented, for example, in the House of Commons on 17 November of last year, 'We must recognise the importance and value of the embryo. The rules governing research on the human embryo must be tightly drawn, as, thanks to the 1990 Act, they already are.' (17 Nov 2000: Column 1198). Similarly, Mrs Ann Winterton (Congleton), points out that 'Even the Warnock committee stressed that "the embryo of the human species ought to have a special status" (17 Nov 2000, Column 1203).

Lobbyists, journalists, government officials, and policy makers are also concerned with the special status of the embryo. We discussed the British parliamentary debates with the director of a medical/scientific lobby group that is active in campaigning for scientists' access to embryos for the purposes of research and treatment. She remembers the ways in which medical researchers and lobbyists felt it was important to educate the public and parliamentarians about embryos, not just by providing 'accurate' scientific facts, but by using visual images of the embryo itself.

In order to win the argument to do embryo research, you had to let people know what embryos [were] – [It was important that] people were able to see it, and, you know, not *contextualise* it particularly well [laughs], but, you know, at least have a vision of what it was. And obviously, from our side of the fence, so to speak, in order to say, 'look, this isn't what you think – might think it is, it's not a - a baby or a foetus or whatever', but by doing so you ... kind of imbue it with importance that might backfire a bit, not that it did. Do you know what I mean?

Embryos were 'special' to parliamentarians both as sacred living things, and as important avenues for scientific research. For people both 'for' and 'against' embryo research, embryos are 'special'.

In addition to being at the centre, as it were, of public and parliamentary debate, the embryo is literally becoming more visible, somewhat like the foetus, now rising above the horizon of its former invisibility to become, if not yet iconic, a powerful 21st century visual image. For example, the embryo is beginning to make appearances within the mass media in brand images, in advertisements, in news programmes, and in various other contexts. As well as images of fertilised eggs and human embryos, images of embryo manipulation in the form of microinjection imagery have become more visible: a clubwear t-shirt, the front page of a national newspaper, in hospital promotional literature. In sum, the embryo has become a more central figure – legally, visually, and culturally – in what might be called the public reproductive imagination.

The commercial embryo - Finally, the embryo has become increasingly central in a commercial sense, sitting at the intersection between genomics and new cell technologies such as tissue engineering. The kind of reconstructed embryo used to make Dolly the sheep epitomises a condensation of the commercial, the genomic and the cellular that now comprises a major biotechnology futures market. Embryos are essential capital accumulation devices - both as conduits for targeted genetic alterations to animals, plants and micro-organisms, and as so-called 'bioreactors' which harness new powers of reproduction for profit.

Embryo as non-centre

All of these ways in which the embryo is centred raise important questions about what its centrality excludes, marginalises or displaces. The ways in which the embryo are centred are not arbitrary, and taking its centrality for granted is very problematic for a number of reasons. In this section, then, we want to problematise the centrality of the embryo by showing it to be plural, paradoxical, peripheral, partial, and produced.

Plural - An embryo is very rarely on its own in PGD or in IVF. It does not really make sense to speak of *the* embryo as a singular entity. Up to 20 embryos are made in any one cycle of treatment. Of these embryos, some will be used for treatment, some may be discarded as pathological or morbid, some may be stored for future treatment, some may be donated to other couples, and some may be donated for research purposes. There are currently probably in the vicinity of at least 10,000 embryos stored at various facilities within the UK alone. Since



human embryos can only be legally stored for five years, this brings us to a second issue about the embryo, which is its paradoxical status as a source of both life and death.

Paradoxical - It is because embryos are 'special' that they cannot be stored indefinitely. This would be irresponsible, since they do not have a known shelf life. Legally, therefore, their shelf life is five years, after which they need to be 'allowed to perish'. This process is often referred to as 'culling'. The irony is that a population produced to create life annually requires a legally mandated culling of this kind.

Embryos are kept because they are also considered 'precious', but some are much more precious than others. Which embryos are considered to be useful for various purposes depends very much on who is evaluating them and under what conditions. For so-called normal IVF, embryo morphology is paramount. For PGD, it is not morphology but genotype that matters.

There are three types of embryos at stake in PGD: 'clear embryos' (ones that do not carry the genetic condition), 'carrier embryos' (which do carry the genetic condition, but will not express it in disease); and 'affected embryos' (those that will express the disease). Ideally, the clinical team wants at least two clear embryos which also have good morphology, but they are prepared to transfer well-developed carrier embryos if there is no alternative, as many carriers can live healthy lives (although they may well encounter the same reproductive issues that led their parents to PGD in the first place). In some cases it is impossible to distinguish carriers from clears, but in the following extract from an interview with a West Midlands couple undergoing PGD, this is not understood to be the case. Leon, the husband, makes a distinction between types of carriers – there can be good carriers (like his wife Michelle, who has no symptoms) and bad carriers (like himself, who have one or two symptoms which have a major impact on his life, although he does not suffer from a disease, as such).

Michelle: Cause last time, we'd actually got *four* good embryos, hadn't we? ...[W]e were called back and were told that we'd got two clear. But when we actually went and had the embryos put back.

Leon [interrupts]: the worst thing was, they got them, haven't they? ... They've got the photos of the eggs and they've got four. And the Professor says, 'This is the *worst* scenario for us ever.' He says, 'Because we've got two clear eggs here and we've got two carriers. We don't know the extent, how they're carrying.' Could be like me, could be like Michelle. If they're like Michelle, no problem. (Yeah). The two *best* eggs were the two carriers.

Michelle: And they *looked brilliant* [emphatic]

Leon: Absolutely fantastic!

Michelle: You could *really* see the difference. [emphatic]

Leon: You could see – The other two weren't as good as them two.

Michelle: They were more granular, weren't they? Like the Professor says, like, 'If we hadn't have done this test and we'd of just took two at random, we would've put the two back that are the carriers.'

Leon: ...And we had to decide: the two clear.

Michelle: The two clear, yeah. The Professor was really pleased. He says to me, 'You've come this far, I'm glad that you've chosen to put the two clear back.'

Several paradoxes become clear in this extract. One paradox is the possibility that a couple will end up reproducing for their offspring the same dilemma they are going through themselves by having children who require PGD. Another paradox which is not evident in this statement per se, but which comes out of the research more generally, is that the process of ovarian hyperstimulation to produce up to forty eggs per cycle, in order to maximise the number of embryos available for testing, especially in PGD, where not all of the embryos can be used – even if they 'look good' - means that it may be the process of IVF itself that introduces a certain level of congenital pathology.



Peripheral - While embryos are very publicly contested and sacralised entities, we have also found, to the contrary, that some couples had never even thought about the issue of there being a moral component to their production or use. As one woman put it to us in response to a direct question about the moral status of the embryo: 'To be honest with you it had never occurred to me to even ask that question until you asked me.'

Similarly, although we have suggested that visual images of embryos have become more common, it is equally true that they are rare, and, more importantly, could be seen to be very dominated still be images of fetuses and babies. We have examined the British press articles we could find on PGD from 1994 to the present (we also looked at some US press, mostly via the internet). An analysis of 45 articles showed that the majority have no illustration. The most common forms of illustration are photos of babies (with or without parents). Some articles showed embryos or fetuses at stages that are much too late for PGD (thus giving a false impression that PGD or 'selection' is done at a stage in which the foetus looks somewhat like a human being). Only one article contained a scientific schematic picture of an embryo at the stage at which PGD is actually done. This seems to indicate that the embryo at the PGD stage is not yet familiar enough to the general public to be represented in mainstream media. In sum, the embryo may be becoming more public, but it is still peripheral. While it is becoming a more recognisable representation of 'life' as Barabara Duden describes it, the embryo is still overshadowed to a large extent by both the baby and the foetus.

Partial and Produced - Like all sociotechnical actors, the embryo always has connections and demands. It does not survive or even exist on its own. The specificities of this claim became clear when one of us went to the embryology lab to watch an embryo being biopsied. The embryologist described how she handles the embryos:

So first of all, there's a couple of things that embryos require. They don't like a lot of light, so obviously they're in the dark. They like to be a particular sort of PH. The reason it's at 62% CO² is because the medium has a carbon base, and in order to keep the medium at the right temperature, we have CO² in the atmosphere.... And that's just the medium. There is the suggestion that too much oxygen in the atmosphere can actually harm the embryos. But data on that is quite ambivalent, most people just stick to 50% CO² and air. Some people actually reduce the amount of oxygen...

The embryo is both a work-object, in the sense of being at the centre of a complex production process, and it is not independent of the many factors supporting it in its various environments. Embryos have to be maintained under very strict conditions, and exist in the midst of complex legal, technical, and temporal requirements.

As a centre, like all centres, the embryo only functions because of a multiplicity of interactions, meanings and practices which congeal to produce its very materiality. The embryo has its (social) life within the technoscientific, regulatory, parliamentary, familial, clinical and emotional multi-logues that our ethnography is attempting to represent.

Conclusion

We conclude, then, that the embryo is in many ways at the centre of PGD, and thus of our ethnography. The embryo's position is at the centre is important and non-arbitrary. It's a matter of a particular historical past and a particular set of practices and discourses in the present that the embryo is at the centre of British discussions and interventions around life, kinship, reproduction and genetic inheritance.

As a centre, the embryo also entails various imagined or anticipated futures. Anticipations of healthy babies, of control over genetic information and disease, and over the vagaries of reproduction are implicated here. We have also tried to show that focussing on the embryo as centre means, as Lucy Suchman mentioned in her paper yesterday, that there materialising forces can 'disappear from view'. Whilst we might want to think about the embryo as centre, it is also important to engage in moving or dispersing this centrality.