

# Fresh embryo donation for human embryonic stem cell (hESC) research: the experiences and values of IVF couples asked to be embryo donors

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**BACKGROUND:** This article reports on an investigation of the views of IVF couples asked to donate fresh embryos for research and contributes to the debates on: the acceptability of human embryonic stem cell (hESC) research, the moral status of the human embryo and embryo donation for research.

**METHODS:** A hypothesis-generating design was followed. All IVF couples in one UK clinic who were asked to donate embryos in 1 year were contacted 6 weeks after their pregnancy result. Forty four in-depth interviews were conducted.

**RESULTS:** Interviewees were preoccupied with IVF treatment and the request to donate was a secondary consideration. They used a complex and dynamic system of embryo classification. Initially, all embryos were important but then their focus shifted to those that had most potential to produce a baby. At that point, 'other' embryos were less important though they later realise that they did not know what happened to them. Guessing that these embryos went to research, interviewees preferred not to contemplate what that might entail. The embryos that caused interviewees most concern were good quality embryos that might have produced a baby but went to research instead. 'The' embryo, the morally laden, but abstract, entity, did not play a central role in their decision-making.

**CONCLUSIONS:** This study, despite missing those who refuse to donate embryos, suggests that debates on embryo donation for hESC research should include the views of embryo donors and should consider the social, as well as the moral, status of the human embryo.

**Key words:** embryo donors / hESC research / fresh embryos / ethics / IVF

## Introduction

There has been much debate on the moral status of the human embryo (Beylveled, 2008; McLean, 2008) and on the acceptability of deriving stem cells from human embryos, since this results in the destruction of those embryos (McLaren, 2001; ASRM Ethics Committee, 2002; de Wert and Mummery, 2003). We aim to add new considerations to these debates by presenting data from a study investigating the views, values and experiences of couples undergoing IVF, who were asked to donate [We are following current conventions by using the language of 'donation'. However, there is a strong case for using the more neutral language of 'provision' (Haimes, 2008).] fresh embryos for human embryonic stem cell (hESC) research.

Our central research question was 'What is the repertoire of perceptions, concerns and views considered by couples who have been asked to donate their embryos for research, as part of the process of deciding whether to donate?'. This study builds on an earlier investigation in the same clinic which indicated broad patterns of donor characteristics (Choudhary *et al.*, 2004). However, that study did not talk directly to the IVF patients about their reasons for donating. The study reported here addresses that gap. (The clinic assisted with access to patients for our social science study, but we followed previous patterns of collaboration in ensuring full ethical and analytical independence from the clinical team.)

Even though IVF patients might be assumed to attach particular value to embryos, since they have strived so hard to acquire them,

they are still a relatively neglected constituency in debates about embryo donation (Haimes and Luce, 2006). Knowledge about their views and experiences contributes to debates about whether it is ethically justifiable to ask them to donate embryos: in particular, to donate fresh embryos during their IVF treatment. It is important for policy-makers, researchers and practitioners to know whether the potential practical gains from hESC research are achieved at social and ethical costs to embryo donors and, if so, what those costs might be. Equally, evidence of good practice in embryo donation needs to be identified so that it might be replicated elsewhere.

## Methods

This research was conducted in one UK clinic. Since little was known about patients' experiences of the request for fresh embryos, a hypothesis-generating, rather than testing, design (based on inductive principles) was followed. We sampled for maximum variation of ideas and perceptions (i.e. heterogeneity sampling, a subcategory of purposive sampling), with the aim of recruiting sufficient numbers to allow thematic saturation to be reached (Silverman 2001, pp. 250–254). All couples undergoing IVF treatment over ~10 months in 2005–2006, who were asked to donate embryos for a range of studies, were contacted ~6 weeks after receiving their pregnancy result, to request their participation in a social science interview. A total of 399 requests were made leading to 46 consent forms agreeing to participate being returned to the authors and, because one couple changed their minds and one couple could not find a suitable time, 44 interviews were conducted; the response rate was 11%. Reasons for non-participation were impossible to judge directly as the authors only had contact with potential participants after they had completed a consent form; this recruitment system was adopted to protect patient confidentiality. A semi-structured interview format was used enabling interviewees to: (i) shape the discussion in ways relevant to their experience; (ii) express views in their own words and thus attach a variety of meanings to what is superficially the 'same' experience or entity; (iii) broaden the scope of the research by raising topics not previously considered; and (iv) challenge others' assumptions. Broad sets of questions covered the following areas: interviewees' demographic details; how they first heard about donating embryos and how they made their decisions; their views of the consent processes; their understandings and views of stem cell research; any previous knowledge or involvement in embryo experimentation; their knowledge of regulation of fertility treatment and hESC science; and their wider awareness of social and ethical issues in this area. All interviews were fully transcribed. Through the hermeneutic analysis of transcripts, using constant comparison and category building procedures, major themes in interviewees' views were identified. This was followed by category mapping and deviant case analysis, to allow inductive theorising (Silverman, 2001).

## Results

There were 30 couples who had had either one (14 couples) or two (16 couples) cycles of treatment; 13 couples who had had three or more cycles; and 1 couple was unsure how many cycles they had had. Of the 44 couples, 27 reported that they thought they had consented to donate fresh embryos to all the hESC research projects in all their cycles of treatment; another 3 couples consented to donate to all projects though not in all their cycles; 2 couples declined to consent to donate embryos to any of the studies; another 10 couples consented

to donate to some though not all studies; and 2 couples were unsure if they had consented to donate embryos.

Five major themes emerged: (i) interviewees' views on embryos; (ii) why and how they made the decision to donate or to refuse; (iii) their evaluations of the consent process; (iv) their understandings of the research projects they were being asked to donate to; and finally, as a cross-cutting theme, (v) the socio-medical context of IVF in which they were asked to donate their embryos. This article focuses on the first theme.

Analysis of interviewees' views on embryos revealed five interwoven subthemes: (i) the experiential lens of IVF through which they viewed the request to donate 'spare' fresh embryos, given their goal of having a baby; (ii) their deliberations over whether the embryo is the same as a baby; (iii) their concerns over the number and quality of eggs and embryos that they produced through IVF and the options for how to use these; (We have termed these considerations the 'calculus of conception' to reflect the persistent mental arithmetic that couples have to perform when calculating the possible combinations of outcomes of treatment.) (iv) their views on the opportunity to see the embryos selected for transfer, on a screen, prior to transfer; and (v) how they spoke about, and compared, the transferred and non-transferred (n-t) embryos.

The first and second subthemes acted as primary reference points throughout the interviews and framed almost everything else interviewees said; we therefore draw attention to this framing here. We have labelled this feature of their discourse 'baby talk' (Haimes *et al.*, 2008). Though not unexpected, this framing needs to be made explicit, given (i) the benefits of hearing from potential donors themselves about their priorities, and (ii) concerns over the difficulty of acquiring embryos (and oocytes) for hESC and other research. Since we deliberately did not ask interviewees directly about associations between embryos and babies, the fact that 'baby talk' emerged spontaneously is a testimony to its strength in framing the interviewees' views. Interviewees saw themselves, first and foremost, as 'IVF patients' not 'embryo donors'.

In the description of the findings that follows, we argue that insight into how and why decisions are made, and the impact of those decisions, can assist the identification of ethically robust ways of improving donation rates, if IVF donation continues to be seen as an appropriate way to source such tissue. However, the highlighting of patients' priorities should not be taken as another reference to the desperate state of IVF patients who are seen as being so focused on babies that they are deemed incapable of making rational observations and choices beyond that of IVF itself (Franklin, 1990). Rather it is a reminder that from their point of view, the research is just another consideration (of many) encountered on the way to achieving their goal. This might also explain the uncertainty about which studies they agreed to donate to, in which cycle of treatment. That which is vitally important to researchers, regulators and some clinicians (the acquisition of embryos for hESC research) is (initially at least) of only secondary importance to the IVF patients. This point was made explicitly by at least 10 couples.

Each subtheme sheds light on how interviewees speak and think about, and act towards, 'the embryo' and shows just how complex and variable these understandings of the embryo are in the IVF clinic, at the interface of IVF treatment and hESC research (Franklin, 2006; Svendsen and Koch, 2008).

## The priority is to have a baby

The following brief extracts provide evidence of where the interviewees' focus lay. As one interviewee said, 'the sole purpose' is 'to have a baby... they're not here to be part of a medical experiment, they're here because they want a baby... obviously you're not just thinking about the research, you're thinking about the whole concept of the treatment that you're going to start and what that's going to mean to your life... [In IVF] you're consciously thinking, "I'm going to have to have all these injections...", so I think you have a lot more on your mind that's probably distracting you away from the paperwork that says "this research we're going to do will be looking at this and that". So some people might just think, "that really doesn't involve me personally, I'll sign that and then think about the consequences afterwards"' (IVF16:430–551). Interviewees apologetically referred to their 'selfishness' or 'greed'. Several said they were happy to donate to research as long as they had first selection of the embryos and only those not useable for their treatment went to research. Whilst it would be 'wonderful' to cure Parkinson's, 'really our priority is just to have a baby' (IVF28:1005–1029). These views are summed up by one interviewee, 'IVF... is such a big thing anyway, especially if it's your first time. [Research is] not really your priority. It sounds selfish but that's the way people think... To be honest I don't think I read the third set of information' (IVF35:493–532).

## Embryos and babies

In the IVF context, the association between embryos and babies is not unexpected. However, the data below show that they were not seen by interviewees as simplistic equivalents.

Therefore 'baby talk' is not meant to suggest that interviewees thought embryos were babies; rather, 'baby talk' framed patients' deliberations, being the initial and most prominent reference point from which other distinctions developed.

One woman said: '... I think in a way an embryo is still a baby. I still think of it as a baby right from day one'. However, the embryo they donated for research was 'unused material, stuff that can't be put back in us for whatever reason, 'cos they don't think it's good enough' (IVF4:885–990). Thus, the first device she employs to explain her views is to draw a comparison between embryos and babies but equally, and at the same time, embryos can be 'stuff'.

Two broad clusters of views emerged from the interviews. The first cluster considers the possibility that the embryo is a baby or could be regarded as a baby, actually or in its immediate potential. One couple described their first reaction at being asked to donate embryos as 'we didn't want anybody to have our babies [laughs], our embryos' (IVF35:229–232). The second cluster encapsulates assertions that the embryo is clearly not a baby and is 'just a ball of cells' (IVF5:215–228), 'a blob' (IVF12:312–349), 'it's this tiny little dot' (IVF17:627–639). However, these interviewees then debated whether the embryo, if not a baby, is nonetheless a living entity. 'At what point does a blob, or speck of cells, divided cells, become a person? Or when does it become capable of thought?' (IVF39:1144–1231).

These two positions do not represent hard and fast groupings to which interviewees could be easily allocated, however; rather, they were clusters of considerations which they voiced as they, for the

most part, struggled to reach a settled view. For example, one interviewee asserted that the embryo is not a baby but expressed the ambivalence and discipline that need to accompany this stance: 'You've just got to get past the fact that [pause] and not think of the egg and the embryo in terms of a child. You've got to still think of it as an egg and an embryo, which is what in fact it is... Unless it's planted inside the womb it's never going to develop into a child and I think you've got to basically remember that it's still an embryo and an egg' (IVF7:573–580). These data indicate how interviewees oriented themselves towards the request and towards the 'entity' they were asked to donate.

## The 'calculus of conception'

We use this phrase to convey the mental arithmetic that patients endlessly perform to calculate their chances of achieving a baby from the number of follicles, eggs, fertilised eggs, cells and embryos they have succeeded in producing. The calculations gain complexity by considerations of quality ['it's drummed into you, it's quality, not quantity that counts' (IVF40:833–852)] and by the choices between different uses of these entities. The request to donate embryos complicated these calculations for interviewees.

Interviewees knew that embryos could be: (i) transferred back to the woman; (ii) frozen (though this clinic has a longstanding policy, which predates involvement with hESC research, of caution towards freezing embryos, due to concerns that it gives couples false hopes about future outcomes, given the likely deterioration on thawing, and also because of the expense of freezing. The clinic only freezes embryos if there are four or more good quality ones left after embryo transfer); (iii) donated to other couples for treatment (though only 1 of the 44 couples interviewed had agreed to donate eggs for the treatment of others; the rest were all less keen on this, from fear that this could result in someone else having 'their' baby); (iv) donated for research; or (v) disposed of without further use.

However, interviewees reported a disparity in what they wanted to do and what actually happened: almost all would have preferred a combination of transferring two embryos and freezing the rest (to alleviate, financially, physically, emotionally, as they saw it, the next cycle of IVF). They remained puzzled, at the time of interview, that they themselves turned out not to meet the dual quantity–quality criteria (especially those who had produced a large number of eggs or embryos). Reactions ranged in intensity. One woman sounded resigned to the fact that she had produced 'quite a lot of eggs' but only four good embryos (IVF7:185–221). Another though was 'shocked' that having produced 26 eggs, 17 of which had fertilised, she had no embryos available for freezing: 'that was quite a smack in the face' (IVF2:186–228).

This type of disappointment is not unusual in IVF, but some interviewees questioned whether these results were related to the research context (see below). They also remained unclear about how the judgement had been made about what to do with the embryos. There was some uncertainty about how the quality of embryos was judged and how this grading affected decisions about freezing or use in research. Again, many (at least 15 couples) said that they were not told much or anything at this stage and this had left them puzzled. They were unclear whether embryos not good enough for transfer or freezing were still good enough for research.

One person expressed these uncertainties: 'We were always told that it would be ones unsuitable to be transferred that would be used, they would never use perfect ones [for research]... Fourteen fertilized, so we were really, really optimistic... when it came to embryo transfer they said they were going to transfer two and I said, "were there any to be frozen for another cycle for us?" and they said, "no", and that was the only answer we got. So I don't know whether that was below the four because I believe it's got to be four perfect ones, then they'll go ahead and freeze them... But they said there was none to be frozen. So maybe there were one or two perfect ones used for research that they couldn't use in the freezing process. I've no idea'. It is important to add that this person immediately said, 'I understood at the time that things would happen that way and I understood fully' (IVF1:439–482). However, she is clearly indicating that there was ambiguity in what was said or in how she understood it.

Those expressing uncertainty also said they felt reluctant to ask for further information, though it is not clear what inhibited them (especially in light of other remarks about the high quality of service provided by the clinic). It might have been that at the time they were so focused on the transferred embryos that they did not consider these other aspects until later (see below). This is a further indication that the IVF process is so consuming of attention and energies that many aspects of the decisions taken did not occur to patients until after the cycle had been completed.

### Seeing embryos prior to transfer

Patients are routinely given the opportunity to see the embryos about to be transferred back to the woman, on a screen beforehand. The majority of couples (34 cases) took this opportunity and found it positive and exciting. Many (19 cases) spoke about the shape and number of cells and their sense that at long last something was happening (17 cases). However, the experience encouraged interviewees to associate the seen embryos with possible future children in stronger terms than previously and this led to mixed emotions.

One woman described how her views of the embryo, and ideas around life itself, were affected by the experience: 'I think I've become far more fascinated by it... when you see five cells on a screen, that's quite a strange sensation... I've suddenly got a lot more respect for how hardy life is. I always imagined before we started the treatment that the eggs and embryos were far more delicate than I now think they are... I feel unlucky that I've had to go through the treatment but I also [feel] very privileged that I've potentially, I've seen my child at five cells which most people just don't get the chance to do' (IVF11:653–697).

At least nine couples decided they did not want to see the embryos in any cycle and two said they would not look on another cycle. The decision though is not easy: '... the second time my husband wanted to see them again and I refused so I had to cover my eyes... I felt that because I'd looked at them I'd developed a relationship [starts crying] and the second time I just thought, "well, I won't look at them and then I won't think about them", but you do [long pause] Sorry, it's dragging up loads of memories [crying]... But even though you haven't seen the rest of your embryos I still feel like I've lost, you know, however many babies... ' (IVF23:590–633).

For another couple, though, the failure to sustain a pregnancy was not a reason for not seeing the embryos in the next cycle: 'we still

really wanted to see them... you've got to think its going to work, you [would] want to have seen them at that stage. But I do think it makes it harder' (IVF40:1092–1106). Once again the imagined child is evident: if the treatment had worked, they would have regretted not seeing the child at that early stage.

Of those who were pregnant, one couple said they wished they had taken a photograph, 'so we could say to our child, "this was you when you were four cells" [all laugh]' (IVF1:833–877). Another couple referred to their child from a previous cycle when they had also seen the embryos, 'we saw her, we don't know which one was her at this early stage... she was being naughty then!' (IVF22:550–561). They imbue the embryos with the child's biography and attributes from this point. Those who were not pregnant tended to have the same conversation with the hypothetical child as those above were having with the actual child, 'you do think that one day it would be a nice story if you got pregnant to say to your child, "I've seen you when you were just four cells big"' (IVF20:723–750).

As we have seen, it was in anticipation of a sense of loss that some couples chose not to see the embryos. However, even those who did not feel the loss as a miscarriage nonetheless used the same frame of reference: 'they put them back in and then I think it's ten days later you come and get a blood test to see whether they've taken and they hadn't, obviously. But I never thought that I'd lost two babies' (IVF6:377–396). Once again the association between embryos and babies is such that these are the terms in which claims that 'embryos-are-not-babies' have to be explained.

Within the context of having agreed to donate to research, the relationship to a projected child could be troubling, on later reflection. Seeing the embryo on the screen, 'turns it into a little person... which is fine, but when you're talking about consenting for stem cells [laughs] and then, you're seeing these embryos and you can see the cells jiggling around, you think, "well...". But by that time you've filled the forms in, but of course you remember that for the next time' (IVF9:1026–1037).

### Comparing the transferred and n-t embryos

Given the impact of seeing (or deciding not to see) the embryos that were to be transferred, it is fruitful to compare interviewees' views on these embryos with the non-transferred (n-t) embryos ones. This provides insight into their views on embryos in general (do all embryos have the same social and moral value, whatever their usage or destiny?) and insight into how they view the embryos that they have donated for research (do these have a different social or moral value, given their particular destiny or presumed lesser quality?). The data suggest that interviewees had little chance to make such comparisons during the IVF process but that later reflection raised further questions for them.

#### *Uncertainty over destiny of n-t embryos*

Interviewees were asked whether they knew what had happened to the embryos that were not transferred. Since most interviewees had few or no embryos frozen, this discussion tended to centre around their knowledge about the other possible destinies for the embryos. Almost all 42 couples who consented to donate to research were unsure whether this had been acted on or even if the embryos were good enough for research. Several described being too

preoccupied with the treatment and the outcome of the embryo transfer to think about the other embryos at that time: 'I can't remember whether anybody said to me they were good enough to be used or not, or whether I asked, because at the time, I was just, "wow, what's going on?" ... I didn't stop and think, it wasn't high on my list of priorities. But if they were used then that doesn't worry me' (IVF6:415–440).

#### *Did they compare transferred and n-t embryos?*

Further aspects of interviewees' views of the relationship between transferred and n-t embryos became apparent when they were asked directly whether they compared the two, and if so, how. One woman said, 'I just feel a sense of loss ... I think at the time it's enormous, but now I don't try to think about that. That's probably why you get upset when you do start to talk about it. But I think you'd go mad if you did think about eleven babies that you could possibly have had and you haven't got one. And so it's scary ...' When asked how she thought about that loss in relation to the decision to donate she replied, 'it's a case of, "if I can't have them then nobody else is going to have them", to give to other couples, but in terms of research then if they're no good to me then hopefully they might be good in some other sense. So that's how I rationalise it' (IVF23:720–739). This theme of 'trying not to think' is not uncommon, though expressed in different ways at different points in the interviews. Another woman said, 'I didn't think about the ones that weren't transferred at all [long pause]. I think I possibly did the first cycle, I think I did and so I purposely don't any more [laughs] ... I think it gets a little bit easier with each cycle ...' (IVF15:580–603). Again there is a sense of a struggle between how much these experiences actually mean and how much they ought to mean, and uncertainty about whether they are being given too great or too little significance.

#### *How were embryos selected?*

Consideration of the n-t embryos entailed reflection on how embryos were selected.

Some were happy with the decision-making process: 'That was the thing that was made clear at the start. They would only use for research what couldn't viably be used for us. So I never ever attached myself to the other ones ... at no point did we say, "Oh I wonder if any of the others could have [worked]". We always knew that the two best ones went in and the rest just weren't suitable' (IVF29:702–43). This group of, approximately eight, interviewees were not particularly concerned either about the destiny of their n-t embryos (beyond their disappointment that not more were frozen) or what happened to them once they got there. They were preoccupied with their treatment and they had little detailed understanding of the physical or social context of the research to which they were donating.

Others questioned how the clinic picked the ones to be transferred: 'she said that they would only pick the ones that are grade one but if there are nine grade ones, I did wonder how did they choose this one and not the other one ... I wish I'd had them all ... for me life starts at conception so I still felt that was life really, even if they weren't going to be implanted'. Her partner commented, 'you just have to trust that they're experienced and they know which ones have a better chance ... I do think life starts at conception but at the same time if you transfer all nine of them then most will not survive anyway, you're better off implanting the ones that are going to survive' (IVF32:539–609).

Another woman said, 'they've probably thrown some good ones away, you don't know' (IVF35:1901–1922).

#### *The troubling third embryo*

This possibility was particularly troubling for a significant subset of interviewees who had more than two top quality embryos but not enough to have any frozen in this clinic. We refer to these as the 'troubling third embryo' (which is a shorthand as some couples could have one, two or three top quality embryos that are neither transferred nor frozen so this phrase includes the 'troubling fourth and fifth embryo' too). This is where the difficulty of satisfying quality and quantity criteria affects couples most. There is far less acceptance or resignation about these embryos than for the other n-t embryos discussed so far. At least 11 couples who were clear that they had at least one top quality embryo that was neither transferred nor frozen struggled with this. One woman who thought she had good quality embryos that were not transferred said she had produced 'six really good quality and we had two go back', so 'the four, they were the leftovers weren't they. They'll have had some really good poke abouts at them. They'll have dug all sorts [out] of them if they were good quality ones ... well, I signed the form, I signed the form, that was [my] decision to make [short pause]. But it's the good ones that upset me, the four little good ones' (IVF18:1718–1741). Another said about the third embryo that could not be frozen, 'I would like to know what other people think, people who are getting more because you can't help thinking at the back of your mind, "hmm, that might be my one chance of having a baby and I've given it away for this research"' (IVF6.2:351–96).

Another, less sanguine, woman described how her understanding of this possibility emerged as she went through treatment and then reflected afterwards. Referring to the early stages of the IVF process she said, '... at that stage it all seemed fairly straight forward to me. The only time I found it much harder was when there was a fertilised egg that they couldn't freeze, and that's when I thought, I wasn't happy with it at that stage ... that possibility had not occurred to me—that you'd have a viable embryo that they would not freeze ... that wasn't covered particularly well and that's the bit afterwards I said to [partner] that I didn't feel happy with that particular situation because that theoretically was just as viable as the ones they put in'. She later said, 'I'd never thought of that possibility ... I didn't know how I was going to feel about anything to be honest, and it was all very, very new ... I was prepared for every other step of not getting enough eggs, or not getting any fertilised eggs, but I wasn't actually prepared for that step of having to throw one away'. She reflected on how much harder the situation would have been if she had not got pregnant. Later she made her point more strongly: 'I felt differently about donating the viable embryo ... because the way I felt it had been worded was, or how I understood it, was all the viable ones would be frozen and I'd obviously not understood that that might not happen. The non-viable embryos that weren't suitable for freezing and the eggs that didn't fertilise, I had no problems with, but as I say, the viable embryo, yes I did'. She returned to this later in the interview, 'I don't think I had really appreciated the emotional aspect of [long pause] the emotional aspect of, wasting my own eggs, if you see what I mean? That, *that* was a loss ...' (IVF14:130–591). It is interesting to note that this couple were pregnant at the time of the interview so IVF had worked for them: pregnancy though did not eliminate the difficulties experienced with this process.

This situation is different from that where interviewees speculate about the n-t embryos that 'might have worked'. Here, they are comparing one, two or three embryos that had at least as good a chance of working as those that were actually transferred. The already-challenging IVF process acquires an additional difficulty when patients realise that such good quality embryos might have gone to research instead, especially for those who would rather not dwell on what that research entails (see below).

#### *Treatment or research?*

This led at least nine couples to question whether research was more important to the clinic than treatment (five of whom also expressed concerns about their troubling third embryos). Couples in this group said they felt that the research agenda was ever present, in the clinic and in the local and national media. One man said, 'They explained everything about the treatment until they were happy that we understood what we were doing, then introduced this secondary part of it... about any products [embryos] that we give them, that can't be used for us, would we be happy and so on, it was always at the end of whatever we wanted to speak about... they had another agenda from what we had, but [we weren't in dispute] with one another. It was done well. It was done professional. In fact, out of all the hospitals and things like that that I deal with, they're easily the most professional that I've ever seen' (IVF19:1452–1470).

Others were less positive: 'Obviously the treatment you get is fantastic but I do believe, and I may be very, very, wrong on this, but I do believe that the [Senior Clinician] is very much into research and I think IVF [short pause] is a sideline for them. I don't think it's their priority. I may be wrong...' (IVF28:160–172). Another said, 'Unfortunately it gives me the impression that the research was the priority and the IVF was just like the bread and butter part of it to fund the research. That's how I felt. And still do... So when I didn't get told about what happened to my embryos and my eggs, or your sperm, you do think, "were you just wanting to keep it for your research because is that the priority?" And I get a little bit annoyed when I talk about it' (IVF9:228–273).

The suggestion that embryos were kept back for research could be considered a serious allegation although such comments were usually made hesitantly or apologetically, accompanied by acknowledgements of the importance of research in general. Interviewees spoke of being reassured when they had raised such questions with clinic staff and also of there being 'proper procedures', but doubts still lingered. One couple decided that they would not consent to the research during their next cycle, wondering if their chances would be better: 'not thinking that anything untoward was going on but we thought that if the option isn't there to use those embryos for research they might then decide they can be frozen. For all that they told us that that wasn't going to be possible, in our minds we wanted to give ourselves the best chance. We weren't saying that anything would happen but you do hear about these things that you just never think of that went on, years ago they're pinching baby parts and keeping them in jars... I mean that's pretty serious stuff... So we just wanted to give ourselves the best chance' (IVF43:892–966).

#### *Knowledge about research*

Those who assumed that their embryos had been used for research had little grasp of what that might entail. Some (eight couples) were

not concerned since they regarded these embryos as 'my throw away bits... it wouldn't upset me to think that somebody in a lab may be messing about and doing experiments with my throwaways, no, it really doesn't bother me' (IVF6.2:545–571). There was some hesitation in referring to embryos as waste material: one couple appeared to correct each other: he said, 'I just got the impression that it was anything that was left over, wasn't it –', at which point his partner interrupted to say, 'anything that was left' and he resumed with, 'anything that was left was going to be used, yeah' (IVF36:581–592), as if the notion of 'leftovers' was not appropriate.

Others, however, were uncertain about how much they wanted to know about the research, with some expressing quite strong discomfort about what had happened to the embryos. One woman said, 'It's just enough to know that you've left your egg or embryo and hopefully it will help, but I wouldn't want to know what was done to it... that would be what I've given to help people but I wouldn't want to know what was done to it' (IVF7:347–363). Another said, 'You'd like to know if it was worth it, if there was some value taken out of them' but '... I wouldn't want to know exactly what they did with them...'. When asked what she was hesitant about, the woman replied, 'I can't put my finger on it... [short pause] because it's still part of you, isn't it... you wouldn't want to know specifically, would you?' (IVF38:392–457).

## Discussion

Briefly summarising the above material, we can see that the interviewees are preoccupied with IVF treatment and the request (and in most part the agreement) to donate is very much a secondary consideration. Addressing the central research question, it is clear that interviewees' views of the embryo are complex and dynamic, changing over the different stages of IVF. The calculus of conception means that initially all embryos are important but as measures of quantity and then quality emerge, they learn to focus their energies on those that have most potential to produce a baby. At that point, the other embryos are less important. On later reflection, they realise that they do not know what happened to those other embryos and they find themselves unable to articulate easily just what they think of those n-t embryos. There is evidence that interviewees sense that the embryos deserve special consideration (it does not 'feel right' to label them 'leftovers') and that the research itself could involve aspects they would rather not consider (this was said with particular strength by a couple who had become pregnant). However, the embryos that caused interviewees most concern were those that held value precisely because they might have been capable of producing a baby but went to research instead: the troubling third embryos. Their value to interviewees lay not in their inherent qualities as embryos but as potential (to become) babies.

From this brief examination of data, we can see that interviewees operate with a complex system of embryo classification. First, there are 'embryos' which represent the vital step of treatment without which no baby could result and which are therefore of enormous value. Once these are classified as apparently good or poor quality, perceptions shift, with patients' energies focusing on the 'good' embryos. The 'other embryos', at that stage, are not given individual attention; they are each one among many that hold no particular individual promise or even value—at that stage. On later reflection,

another sense of that n-t embryo (or embryos) emerges but during the treatment itself that embryo diminishes in importance. Attention shifts instead to 'our embryos': that is, those that could be seen on the screen, that were transplanted and which might, or did, produce a pregnancy. Sometimes 'our embryos' were frozen, if enough were produced, to be used for later attempts. The distress caused by the 'troubling third embryo' is precisely because those good quality embryos that went to research should really have been among 'our embryos', from the interviewees' point of view. Finally, interviewees clearly held a version of 'the embryo', the morally laden, but to them abstract, entity that they were aware was the subject of debate and which they felt deserved respect (hence the apologetic use of 'leftovers'). However, this category of embryo, though not irrelevant, did not play a dominant role in their decision-making.

Therefore, the interviewees' views differ from those who debate the moral status of the human embryo (from any position) since they start from a different framework of relevance, one that is dominated by the IVF context and experience. Arguments about potentiality and capacity can be found in their utterances (Haimes *et al.*, 2008) but these are embedded in their calculations of quantity and quality, and good and bad embryos, rather than in a view of the inherent qualities of embryos *per se*. This embryo classification scheme suggests that debate about the acceptability of hESC research should be broadened beyond that of the moral status of the human embryo to encompass also the variable *social* status of embryos. These data also suggest that the moral and social status of embryo *providers* should be included in deliberations.

The main weakness of this study is insufficient representation of those who completely refused to donate embryos to stem cell research. Previous studies have found variation in the numbers refusing. Bjuresten and Hovatta (2003) reported only 8% of those asked refused, while a larger UK study found 46% refused (Choudhary *et al.*, 2004). Hug's (2008) review of the literature on decision-making about donation of embryos suggests that being at the beginning of treatment, not understanding the purpose of research and having good quality embryos, all influence potential donors to refuse. However, these factors were also important to our interviewees, so they cannot be determinative of the final decision. We were able to elicit the views of only two refuser couples: in both cases, they objected to what they saw as possible animal research rather than the treatment of the human embryo. Therefore, it is likely that the views of those with a strong moral objection to either embryo experimentation and/or stem cell research are underrepresented here. Although it is less likely that strong opponents of embryology would use IVF at all, it is unclear whether refusers have particular objections to stem cell research. Other research suggests that access to 'refusers', to elicit their reasons for non-donation, is often difficult so it might be that such people are 'research refusers' in general. There are also tentative suggestions that refusers in these contexts are less trusting of either the institutions involved in the research or the explanations given for the research (Haimes and Whong-Barr, 2004; Haimes and Williams, 2006). This, together with the findings of Choudhary *et al.* (2004), may also explain the low overall response rate in our study. The relevance of such possibilities for the embryo provision context clearly needs further exploration.

The strengths of this study lie in its original insights into the debates around the use of embryos for hESC research. First, this study focuses

on the provision of fresh embryos, an aspect that has received little attention hitherto. Although there are several studies on the choices potential donors might make with their frozen embryos (van Voorhis *et al.*, 1999; Leach Scully and Rehmann-Sutter, 2006; Lyerly *et al.*, 2006; de Lacey, 2007a, b; Fuscaldo *et al.*, 2007; Lyerly and Faden, 2007), few have studied the particular considerations that arise when requests for donation to hESC research are made during the IVF process itself. A brief report of a Swedish study of the acquisition of fresh embryos for hESC research reported the 'positive attitude' of donors (Bjuresten and Hovatta, 2003, p. 1355) though that study had similar difficulties to ours in discovering why some patients refused. Also that study, though valuable as an early investigation in this field, lacks an in-depth understanding of donors' values and perceptions and does not explore the impact of combining IVF with requests to donate. Our study usefully provides both those elements.

It has been argued that the 'intensely pressured context in which women create eggs for IVF' (Cohen, 2000) has such an impact that requests for donation to research should only be made in relation to frozen embryos (McLeod and Baylis, 2007). The American Society for Reproductive Medicine Ethics Committee argued that 'it is appropriate to use only spare embryos that have been frozen' while acknowledging that questions would arise about the possibility of using fresh embryos because of their potentially better quality (ASRM Ethics Committee, 2002, p. 959). However, studies on patients' decision-making over the range of possible fates of their frozen embryos suggest that this raises many difficulties for patients (Fuscaldo *et al.*, 2007) and is subject to change (Newton *et al.*, 2007). de Lacey suggests that these problems could be resolved by making decisions about the futures of embryos before any are frozen. Our study contributes to her call to explore how this 'moral reasoning could be facilitated' (de Lacey, 2007b, p. 1757). It is clear, though, that requesting only frozen embryos would not resolve all difficulties for embryo providers.

Another valuable aspect of this study is the presentation, from the providers' point of view, of the complex detail in which they perceive embryos. It is not uncommon in earlier studies to suggest that patients think of the embryo as a child (Laruelle and Englert, 1995; Nachtigall *et al.*, 2005; Svendsen and Koch, 2008). However, our study adds greater depth to such observations and shows that the conceptual relationship between 'embryo' and 'child' is much more nuanced, subtle and contextualised (and therefore variable) than such earlier claims allow (de Lacey, 2007a, b).

A further contribution is the provision of in-depth empirical evidence to question the oft-used adjective of 'spare' in relation to embryos. Although this has been raised conceptually (Holm, 1993; Svendsen and Koch, 2008), we now have evidence (particularly data on 'the troubling third embryo') that donors' understandings of 'spare' might not match that of clinicians, researchers or ethicists. Previous studies have tended to use this phrase rather loosely and variably. Evidence from our study suggests the need to have a very explicit discussion with potential donors about what this phrase actually means in practice in any particular setting, both in relation to fresh embryos and in relation to local freezing policies.

These new insights into the debates on the uses of embryos for stem cell research suggest a number of conclusions and recommendations, on the question of whether it is ethically justifiable to ask IVF patients to donate fresh embryos. First, while requesting fresh

embryos is not without its problems, it would appear that these interviewees regarded this as a reasonable request. There is some suggestion in data under the theme of 'understandings of research' that interviewees did not grasp all the details of the projects they were contributing to, such as the issue of immortality of stem cell lines, but that could be an objection raised about any request to contribute to hESC research, not whether embryos are fresh or frozen.

However, a second conclusion is that requests for fresh embryos should not be made in a patient's first cycle of IVF. Although there were no overt objections to the research request itself, many interviewees raised the issue of how stressful and busy IVF is, particularly in the first cycle when 'so much is going on' and it is all very unfamiliar to the couple. Combining this sense of confusion and stress with the data above on the variability of patients' views of the embryo as they go through the different stages of IVF suggests that patients need to experience one full cycle, and thus experience this variability, before they can fully appreciate what it might mean to them to provide an embryo for research. Delaying the request until the second cycle also improves the patients' chances of fully understanding the different possible definitions of 'spare embryos'. In short, waiting until the second cycle improves the chances of consent being more fully informed and being based on experience as well as on counselling and documentation (Manson and O'Neill, 2007). This delay also provides some of the distance that proponents of only asking for frozen embryos suggest is needed to ensure patients make autonomous decisions, while avoiding some of the additional problems associated with decision-making over frozen embryos. Adopting such a strategy would also be an effective response to those patients who question the priorities of IVF clinics involved in stem cell research.

Several questions arising from this study would benefit from further consideration. For example, now that embryo donation is more widespread, how do these findings from a UK clinic compare with those in other countries? Some comparative work has already been conducted (Leach Scully and Rehmann-Sutter, 2006; Haimes *et al.*, 2008) and more is being explored, e.g. in China (Mitzkat *et al.*, 2009) and elsewhere, through an international network of studies on providers' perspectives. Also this and other studies very usefully establish the importance of exploring donors' perspectives and experiences, and establish the importance of women's reproductive labour in global tissue economies (Cohen, 2000; Waldby and Cooper, 2008). However, it remains unclear just what weight such aspects are, or should be, given in the policy-making process in these areas.

What is clear though is that this study adds to our understanding of the wider social implications of stem cell science. Much of the socio-ethical material on hESC science hitherto either addresses the therapeutic end goals of such work or the moral status of the embryo. This article opens up for discussion the 'black box' of the provision of embryos and gives us greater insight to a key early point in the process of hESC research, without which progress would be very slow indeed.

## Author's role

E.H.: substantial contribution to conception, design, obtaining funding, analysis and interpretation of data. Substantial contribution to drafting and critical revision of article. K.T.: substantial contributions to interpretation of data, drafting and critical revision of article.

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