NO SMALL MATTER FOR SOME: PRACTITIONERS’ VIEWS ON THE MORAL STATUS AND TREATMENT OF HUMAN EMBRYOS

BOBBIE FARSIDES AND ROSAMUND SCOTT

Brighton and Sussex Medical Schools, Centre of Medical Law and Ethics and School of Law, King’s College London
rosamund.scott@kcl.ac.uk

ABSTRACT

In this paper, we discuss findings from two studies designed to access and analyse the beliefs, attitudes, and behaviours of health-care professionals and scientists working in morally contested fields of biomedicine that involve the embryo. We seek to support the view that the embryo typically ‘matters’ to the people we interviewed and whose work we observed, even though it is impossible for them to agree in terms of why that is, and even though their work is of the type to which the moral guardians of the embryo object. In the first part of this paper, we touch on the policy and legal position in relation to embryos, noting Margot Brazier’s account of the development of the relevant regulation in the UK and the importance of her claim that the embryo is widely thought to have an important symbolic value. We then turn to explore some of the views, attitudes, and work practices of those whose work involves the embryo, whether that be in relation to fertility treatment services, including IVF and PGD, or research that uses embryos. Our discussion shows the extent to which the embryo typically matters, in various ways, to those working in these fields.

Keywords: moral status of the embryo, treatment of the embryo, health professionals’ and scientists’ views

I. INTRODUCTION

The moral status of the human embryo is a disputed matter, and has continued to be so long after the legal approach to its treatment and use was set out in English law. It is not an exaggeration to say that people will probably never agree about when human life acquires moral significance, with the range of possibilities spanning from conception to beyond birth. These disagreements will then go on to have
significance in relation to similarly contentious moral issues, such as ter-
mination of pregnancy and stem-cell research. As medical technologies
advance, the potential uses for human embryos expand and the ways in
which we can test and adapt the embryo become more numerous, the
arguments will no doubt continue.

In this paper, we discuss findings from two studies designed to access and
analyse the beliefs, attitudes, and behaviours of health-care professionals
and scientists working in morally contested fields of biomedicine that
involve the embryo. The first study, on which we concentrate here,
focused on those working in *in vitro* fertilisation (IVF), but particularly
preimplantation genetic diagnosis (PGD); the second looked at those
working in IVF, PGD, and stem-cell research, and focused on the donation
of so-called ‘spare’ embryos to research, including stem-cell research.¹

Through our discussion, we seek to support the view that the embryo
typically ‘matters’ to the people we interviewed and whose work we
observed, even though it is impossible for them to agree in terms of
why that is, and even though their work is of the type to which the
moral guardians of the embryo object. For this reason, we believe that
their experience of working together and accommodating moral differ-
ence will resonate with our friend and colleague Margot Brazier who,
throughout her career, has found ways of working productively with
those with whom she disagrees, sometimes profoundly.

We hope that Margot would not mind us saying that although she has
strong and well-formed views of her own which inform her work and
help define her personal response to legal and ethical issues, at the
same time she remains capable of accommodating difference, encour-
gaging debate and—where appropriate—seeking consensus. These
skills have been apparent on numerous occasions, and in part explain
her long-standing and successful working relationship with her Man-
chester colleague John Harris, with whom she long ago agreed to dis-
agree on a whole range of important issues.

¹ Study 1 was entitled ‘Facilitating Choice, Framing Choice: the Experience of
were Clare Williams (PI), Kathryn Ehrich, Bobbie Farsides, Jane Sandall,
Rosamund Scott, and Peter Braude. Clare Williams and Kathryn Ehrich con-
ducted the interviews, and Bobbie Farsides ran the follow-up ethics discussion
groups (EDG’s). We would like to thank all those who participated in this re-
search and also the Wellcome Trust Biomedical Ethics Programme for its grant
(Grant no: 074935). Study 2 was entitled ‘Ethical Frameworks for Embryo
Donation: Views, Values and Practices of IVF/PGD Staff’, August 2007–
June 2010, funded by the Wellcome Trust Biomedical Ethics Programme,
Project Grant No 081414. Clare Williams was the PI, Kathryn Ehrich con-
ducted the interviews, and Bobbie Farsides ran the follow-up ethics discussion
groups (EDGs). Also on the team were Rosamund Scott, Sarah Franklin, Lene
Koch, Sue Avery, and Peter Braude. Once again, we would like to thank all
those who participated in the research as well as the Wellcome Trust for its
support.
In the first part of this paper (Section II), we touch on the policy and legal position in relation to embryos, noting Margot’s account of the development of the relevant regulation in the UK and the importance of her claim that the embryo is widely thought to have an important symbolic value. We then turn (in Section III) to explore some of the views, attitudes, and work practices of those whose work involves the embryo, whether that be in relation to fertility treatment services, including IVF and PGD, or research that uses embryos. Our discussion shows, we think, the extent to which the embryo typically matters, in various ways, to those working in these fields.

II. POLICY AND LEGAL BACKGROUND

The fact that people still disagree about the moral value and worth of the embryo is reflected in a number of recent public policy statements. For instance, in its 2005 report, Human Reproductive Technologies and the Law, the House of Commons Science and Technology Committee observed:

> We accept that in a society that is both multi-faith and largely secular, there is never going to be consensus on the level of protection accorded to the embryo or the role of the state in reproductive decision-making... We believe, however, that to be effective this Committee’s conclusions should seek consensus, as far as it is possible to achieve. Given the rate of scientific change and the ethical dilemmas involved, we conclude, therefore, that we should adopt an approach consistent with the gradualist approach, of which the Warnock Committee is one important example.\(^2\)

In its response to the Committee’s report, the government stated:

> While it has been argued that there have been many scientific developments and changes in social attitudes, the Warnock Committee’s approach to the status of the embryo remains valuable. While this gradualist approach to the status of the embryo may cause difficulties in the drafting of legislation we believe that it represents the most ethically sound and pragmatic solution and one which permits in vitro fertilisation and embryo research within certain constraints set out in the legislation.\(^3\)

---


We return, then, to the Warnock Report itself, which preceded the Human Fertilisation and Embryology (HFE) Act 1990 that now (as amended by the HFE Act 2008) regulates treatment services involving the embryo as well as embryo research. The report held that, although of low moral status, embryos are entitled to ‘respect’.\(^4\) What this means or entails is a deeply interesting and important question, both in relation to the clinical and research work that involves the embryo and the ethical, legal, and public policy positions and debates that surround these practices. Some might argue that Warnock was too ready to move on from the question of why the embryo was worthy of ‘respect’, concentrating on what respect entails in practice:

Although the questions of when life or personhood begin appear to be questions of fact susceptible of straightforward answers, we hold that the answers to such questions in fact are complex amalgams of factual and moral judgments. Instead of answering these questions directly we have gone straight to the question of how it is right to treat the human embryo.\(^5\)

However, it is important to remember that the report was written at a time when science was thought to be running ahead of the ethics needed to govern and possibly constrain it. A pragmatic approach that looked to place limits acceptable to scientists and clinicians (as well as the society within which they operated) was the order of the day. That said, it is also important to acknowledge that—since Warnock—advances in scientific and medical research have been accompanied and often preceded by timely and sophisticated moral debate. What is more, this debate is no longer the preserve of academic commentators and/or moral or religious stakeholders. As our research shows, despite the policy and legislative framework, the status of the embryo remains a live issue within the very laboratories and clinics that are at the forefront of scientific advance.

Reflecting briefly on the legislative framework before we turn to consider the views of those who work with the embryo, Brazier has argued persuasively that the ‘driver’ for regulation in relation to the embryo in the UK was in fact developments in embryo research.\(^6\) Under the subsequent HFE Act 1990, research on so-called ‘spare’ embryos could, with the consent of the gamete-providers,\(^7\) only be directed to purposes


\(^5\) Ibid, para 11.9, our emphasis.


\(^7\) HFE Act 1990, Sched 3, paras 1(1) and 2(1).
connected with fertility and reproduction and only for the first 14 days of embryonic development. While the so-called 14-day rule has remained, the scope of permitted research was broadened by the Research Purposes Regulations 2001, and further clarified and put on a statutory footing by amendments made in the 2008 Act. Permissible research purposes now transcend those relevant to reproduction per se, and include:

... (a) increasing knowledge about serious disease or other serious medical conditions, (b) developing treatments for serious disease or other serious medical conditions, (c) increasing knowledge about the causes of any congenital disease or congenital medical condition that does not fall within paragraph (a).

A significant aspect of embryo research now includes stem-cell research and the attempt to create stem cell lines. Seen in one way, then, research on the embryo can now be directed not just towards the goal of creating life, but also that of improving its quality.

Strikingly, Brazier has written about the way that—for anyone who cares about the embryo—it is unsatisfactory that it has increasingly come to be seen as an ‘artefact’. At the same time, she recognises that the notion of an embryo having the status of a human being with corresponding claims does not (unfortunately as she sees it) represent public opinion in the UK. Nevertheless, she emphasises the ongoing attempts to agree an ‘intermediate’ status for the embryo, drawing attention to the requirements of Article 18 of the Council of Europe Convention on Human Rights and Biomedicine. Importantly, she also reminds us of the ‘symbolic’ nature of the embryo (recalling the controversy over ‘orphaned’ embryos) and, perhaps rightly, characterises British thinking about and legislation regarding the embryo as ‘muddled’.

In what follows of our discussion of the views and concerns of health professionals and scientists working in the clinical contexts of IVF and PGD or in the laboratory setting of embryo research, while some of this ‘muddle’ may be apparent so too, we think, is much of this ‘special’ nature of embryos. It is this aspect that we would particularly like to bring out in recognition of Brazier’s personal views about the embryo (as she has expressed these in her work) and the significance of her claim that embryos do in fact have an important ‘symbolic’ value for many people in the UK. The claim we wish to make, in tribute to Brazier’s work, is that—surprisingly perhaps—this holds true also for

---

8 HFE Act 1990, ss 3(3) and (4); and Sched 2, para 3(2).
9 HFE Act 1990, as amended by the HFE Act 2008, Sched 2, para 3A (2).
10 Brazier, above, n 6, 187, 188.
11 Ibid, 188.
many of those working in the clinical and research fields that involve the embryo.

III. THE CURRENT LOCATION AND POSITION OF THE EMBRYO

Over twenty years post-Warnock, we live in a world where the embryo has become a ‘work object’, or an ‘artefact’, to use Brazier’s term, for a range of health-care professionals and scientists. The embryo is worked upon in a variety of settings and for a range of purposes: to create a child, to ensure a healthy child, to ensure a tissue match for an ailing sibling, or to contribute towards healthier futures through advancing medical research and treatments. In all these settings, the biological definition of the embryo is constant, as are the legal limitations placed upon its storage and use.\(^{12}\) Individuals and teams conduct their increasingly complex professional responsibilities against a background of personal beliefs and values, which may or may not make that work more difficult. Further, persisting social representations of their work as ‘ethically challenging’ mean that, irrespective of their own position, they are aware of being under an ethical spotlight. While media portrayals of health professionals’ and scientists’ work is rather simplistic and sometimes polarised, in reality staff hold a range of views about when life begins, about when an embryo becomes morally significant, and about the acceptability of embryo discard or donation to others or to research.\(^{13}\)

Indeed, for the professionals who interact with it, the ethical significance of the embryo is not officially pre-determined. Instead, for some, a pre-existing commitment to a particular account of the moral status of the embryo means that they sometimes face an additional task of accommodating their own views within their professional framework and practice. For others, the embryo may be invested with a variety of meanings and significance by those who have an interest in its possible futures: the would-be parent, the carrier of a devastating genetically inherited disease, or the willing donor will define what the embryo means to them; in turn, many professionals will borrow the interpretation of moral status provided by those who requested their interaction with it rather than imposing their own.

Before discussing some of these views, we briefly describe how our research was conducted and clarify the claims we make in relation to it.

\(^{12}\) As governed by the HFE Acts.

\(^{13}\) We discuss media portrayals of this kind of work further in K Ehrich, C Williams, and B Farsides, ‘The Embryo as Moral Work Object: PGD/IVF Staff Views’ (2008) 30/5 Sociology of Health & Illness 772, 774.
A. Our Approach to the Research

With Ethics Committee approval, Study 1 used multiple methods to research the work in two sites, both Assisted Conception Units (ACU) in teaching hospitals in England, offering a mixture of National Health Service (NHS), private, or ‘self-funded’ NHS treatment. The clinics offer a range of services including IVF to women and couples who need fertility treatment, and PGD, which requires many of the same procedures and technologies. Our research included observation in clinics, interviews with a range of health professional and scientific staff, and ethics discussion groups (EDGs) facilitated by a philosopher working in medical ethics. This paper draws on the set of twenty-six staff interviews and five EDGs from our first study site, generated between May and December 2005.

In Study 2, with Ethics Committee approval, we again employed multiple methods in our visits to three UK sites which provide IVF (and one of which provides PGD) and which are also involved, directly or indirectly, in the provision of embryos for stem-cell research. Across these sites, we interviewed 44 health professionals and scientists and a philosopher working in medical ethics conducted six EDGs. This research was conducted between 2007 and 2009.

We discuss views and present quotes selected from the interviews and the EDGs to show the variety of views held by people doing the same kind of work. Our findings are limited to their specific contexts and we do not make claims as to their generalisability to other sites within the UK or to settings outside the UK.

B. The Diversity of Views regarding the Embryo

From the outside, it would be easy for observers to assume a uniformity of views regarding the status and treatment of the embryo among those whose work entails the possibility of its destruction. However, as we will illustrate, there exists an interesting diversity of views. This may mean that individuals need to accommodate their personal views and values with their professional roles and it may affect the way in which individuals and teams practice. In this regard, in earlier research of ours in which we identified a diversity of views about the fetus among health professionals and scientists involved in prenatal screening, diagnosis, and selective abortion, we characterised some staff as ‘tolerators’, some as ‘facilitators’ and noted that there were likely to be few ‘absolutists’ working in this area.14

---

A difference in approach to the status of the embryo might be expected dependent upon where the embryo is being worked upon—the clinic (including its laboratories) or the laboratory (as in the stem-cell laboratories). Similarly, the type of work a person can feel morally comfortable doing might be bound up with the view she holds of the embryo and from whence she derives her account of moral status. Given the variety of ways in which the embryo can become part of the embryologist’s working day or the scientist’s laboratory, it should not be surprising that individuals see the context within which the embryo is being worked upon (clinic or laboratory) and the route via which it has come into their possession as morally relevant. For this reason, we have framed our discussion under three headings which indicate the location and the work being carried out on the embryo.

1. Embryo as Reproductive ‘Tool’
For those focused on the creation of a child, or a healthy child in particular, we found a range of views expressed about the embryo.

For some, it is ‘just a bunch of cells’ (Study 1, Scientist 3). For others, the embryo (although still perhaps a collection of cells) is ‘definitely special... because it has this potential’ (Study 1, Embryologist 5). Embryologist 15 (Study 1) sees embryos not as humans but ‘as potential’. Participants’ use of the word ‘potential’ is unlikely to be linked to a particular moral account of the status of the embryo, but rather perhaps shows their awareness of the ‘special’ nature of embryos. In relation to the idea of potential, some IVF staff made distinctions about the nature of this potential, depending on whether the goal was the creation of a baby (as in ‘straight’ IVF) or a ‘healthy’ baby (as in PGD). PGD, which involves removing a single cell from a day 3 embryo and testing it for a serious genetic condition, relies in the first instance on IVF, and could well entail the destruction of some embryos that would otherwise have been transferred in IVF per se, a point that could be problematic for ACU staff, some of whom were ambivalent about the prevailing policy acceptance of destruction of the pre-14-day ‘affected’ or ‘spare’ embryos. This was one example of the way in which

---

16 As we observe in Ehrich, Williams, and Farsides, above, n 13, 784.
17 Ibid, 779.
18 For further discussion, see K Ehrich and C Williams, ‘A “Healthy Baby”: The Double Imperative of Preimplantation Genetic Diagnosis’ (2010) 14/1 Health (London) 41, 51.
19 We discuss this further in Ehrich, Williams, and Farsides, above, n 13, 785.
views differ, not only about the status of the embryo but also about issues such as embryo donation and discard.

This diversity of views about the embryo, and the appropriateness of its treatment, was typically accompanied by an accommodation, on the part of other members of staff, of these differences of opinion. We saw examples of this in the EDGs. For instance, in one EDG Counsellor 10 said: ‘I think as a PGD team we’re very good and we have meetings on a routine basis... I don’t think I’ve been to a meeting where we haven’t discussed one of these issues, and we don’t always agree round the table’. At the same time, despite differences of opinion in any given case, the group is faced with the goals of their work, goals which mean (or include) that individuals have to work well together as a team. And in another EDG, when most of the contributions were from those who held the ‘just a ball of cells’ view, Counsellor 28 observed: ‘I have no problem discarding embryos, from a personal point of view. But some people do. And I can understand why they do’.

Indeed, exploring further the range of views about the embryo, Nurse 4 (Study 1) described the embryo as ‘a life’ and Doctor 24 (Study 1) as ‘the start of life’. Some staff in fact described embryos as ‘beings’ and ‘babies’, a view that was perhaps surprising because it might be a linguistic form more commonly adopted by those who oppose PGD (or the use of embryos in research). Scientist 2 (Study 1) regards embryos as ‘little beings’ from conception, and Doctor 6 (Study 1) advises patients, ‘we’re replacing two embryos or two little babies’. These latter participants expressed some mixed feelings when they talked about working with embryos and were more concerned about the fate of embryos that are not selected for transfer.

However, even where staff characterise the embryo as a potential baby, its survival will be contingent upon its suitability to this end, with the poor quality embryos being discarded, and the number of embryos being transferred limited in the interests of avoiding multiple births and harm to subsequent children, and those remaining that are of sufficient quality perhaps being frozen for future possible use.20 To the extent that an embryo is a means to an end, it is a means to the end first designated for it, the creation of a child. Where the process

---

20 For the policy background to the HFEA’s current policy on the number of embryos that may be transferred, see eg HFEA Expert Group on Multiple Births after IVF, One Child at a Time: Reducing Multiple Births After IVF (HFEA, London October 2006). Available at <http://www.hfea.gov.uk/docs/MBSET_report.pdf>. Current figures are that more than 25% of IVF pregnancies in the UK are still multiple, that is, 40% of all IVF births are twins or triplets. See <http://www.oneatatime.org.uk>. For current relevant policy guidance on embryo transfer, see HFEA, Code of Practice (8th edn HFEA, London 2009), Ch 7.
fails and embryos are not of sufficient quality to justify transfer, there
may be genuine sorrow at the lost opportunity, but disposal is less eth-
ically fraught due to the fact that what is being discarded was unlikely to
lead to a viable pregnancy.

The value of the embryo is sometimes defined with reference to the
wishes and priorities of would-be parents. In this process, staff may
find themselves prioritising reproductive autonomy, and parents’ inter-
ests in having either a child or, specifically, a healthy child over their per-
sonal views about the embryo. For instance, Embryologist 26 (Study 1)
supports abortion and a woman’s right to exercise reproductive choice,
even if this causes personal conflict: ‘If you feel you’ve done the best you
can for the patient and this is their wishes, it tugs at your heart strings to
throw away a beautiful embryo, but if it’s what they want, then so be it.’
And questions about the value of human life at the three-day-old
embryo stage may be deflected by prioritising instead the goals of
giving women reproductive choice, helping to create ‘healthy babies’,
and being part of a good team.21

We now turn specifically to the treatment context of PGD, and the
goal of enabling the birth of a ‘healthy’ baby.

2. Embryo as Entity to be Tested

For those involved in testing the embryo for disease, the embryo’s sur-
vival is tentative, and dependent upon their announcing it both
healthy and robust. If it is affected with the disease it will be rejected,
as disease avoidance was the very purpose of the exercise and by law
these ‘affected’ embryos cannot be ‘preferred’ in treatment Ibid, T86
and Ibid, T87. This leaves scope for disagreement over whether such se-
lection is morally acceptable per se, or whether it is permissible only in
conjunction with an account of seriousness (of a given genetic condition
in a future child) that people can agree on. Our research indicates that
selection per se is typically not viewed favourably by those working
with the embryo and that some notion of ‘seriousness’ (as a reason to
create and test embryos) is customarily very important to them. Our
work also reveals the extent of concern about the avoidance of
embryo wastage as a result of PGD.

a. ‘Respect’ for the Embryo—Significant Risk and Seriousness as
Criteria for PGD Testing

One way, perhaps, that the embryo might be thought to be ‘respected’ is
by means of limits placed on the legal criteria for the testing of embryos.
Those working in the field of PGD are working with criteria that hinge

21 We discuss this further in K Ehrich, C Williams, and B Farsides, above, n 13,
784.
on the idea of a ‘significant risk’ of a ‘serious genetic condition’. In this light, Scientist 21 (Study 1) observed:

I would say our role was to enable somebody to have a healthy baby when, in the first instance they’ve got a fairly substantial risk of having an unhealthy baby. And so I guess... the dividing line then is, what you classify as healthy and unhealthy and how severe...

The degree of risk of a given condition in a future child was addressed in several of the discussion groups. Some staff saw risk in quantitative terms. For instance, Scientist 19 (Study 1) referred to the idea of a ‘significantly increased risk above population risk’. Another member of staff (Nurse 13, Study 1) commented that if the risk is greater, this helps you to ‘feel easier maybe about what you’re doing’. The relationship between the criteria was also noted in discussions. For instance, Scientist 2 (Study 1) commented that although there may only be a risk rather than a certainty of a condition occurring in a child, the risk could relate to a very serious condition.

The criteria must be interpreted with reference to guidance in the HFEA’s 8th Code of Practice, which includes, for instance, ‘the views of the people seeking treatment in relation to the condition to be avoided, including their previous reproductive experience’. This may well be appropriate since (as has been observed by us and others, including the Human Genetics Commission), it is very difficult, and perhaps impossible to define ‘serious’. This is because people disagree about what this means, a point that was frequently noted by those we interviewed and in the EDGs. For instance, Doctor 24 (Study 1) said ‘[w]hat I feel is serious, minor, is a very subjective issue especially to parents’. Counsellor 18 (Study 1) said that ‘[w]e all have a different idea of what it is’. Differences of opinion about seriousness were also noted by Embryologist 33 (Study 1): ‘I think how one person copes with it and how another person copes with “serious” is going to be different as well... What one person thinks is a serious condition, the next person might not.’

---

22 These criteria were those originally developed by the Joint Working Party of the HFEA and HGC and published in the Outcome of the Public Consultation on Preimplantation Genetic Diagnosis, 2001. They are now instantiated in the HFE Act 1990, as amended by the HFE Act 2008, Sched 2, para 1ZA.

23 HFEA, above, n 20, para 10.6. At the time of our research, the wording was slightly different but the substance was the same.

Health professionals’ and scientists’ engagement with any given couple seeking treatment, in which they learn about the couple’s and family’s experience, may well affect their views about the issue of ‘seriousness’. For instance, Doctor 11 (Study 1) observed: ‘[K]nowing the couple can have an amazing effect on how you feel about them.’ Staff views in general on this point were well caught by Scientist 2’s (Study 1) observation that ‘you have to be able to see patients’ perspectives’. There were also many observations that revealed great empathy with couples in the light of their family experience to date. For instance, in relation to cancer in the family, Nurse 4 (Study 1) observed:

So if someone felt so passionate about it, I don’t feel that I can judge or say what they—because I don’t know, unless you’re in someone else’s shoes, I don’t feel that we can make such a judgment really. So if someone has got a family history, a very strong family history of cancer, then...who am I to say?

Amidst reflection on the importance of gaining awareness of people’s actual experience of conditions, there was discussion of the vital role of staff discussions about particular cases, which were reported to occur regularly.25 In our view, these show how important it is for staff to feel as comfortable as they can with the acceptability of PGD for a given condition.

Indeed, despite a great deal of empathy for those coming through for PGD testing and despite awareness of the difficulty of ‘pinning down’ seriousness, our participants seemed to feel that there must be a limit to what could be seen as a ‘serious genetic condition’. For example, Scientist 2 (Study 1) observed: ‘[W]hen it’s serious, their life is completely debilitated by it...it’s medically serious’. Later, he/she added: ‘If we said the possibility is it’s going to be mild, we wouldn’t do PGD for it. But if the possibility is there that it’s going to be fairly serious, that’s why it’s done.’ As for other conditions that may not be serious, Nurse 13 (Study 1) suggests that a condition such as cleft palate is not serious, although ‘people are clamouring for’ the relevant testing.

What these observations show, and we do not think this is surprising, is that health professionals and scientists have a range of views about which conditions will in fact satisfy the criterion of ‘serious genetic condition’. In turn, this affects their sense of what is an ‘acceptable’ request for PGD, entailing—as it does—the creation and possible destruction of embryos. For instance, in response to the interviewer’s question,

‘[s]hould we always give patients what they want?’, Doctor 14 (Study 1) responded: ‘No, no. It’s not in absolute terms. They want it for a legitimate reason.’

Significantly, we suggest that this emphasis on a degree of seriousness, understood empathetically with reference to the prospective parents’ and family’s experience, can in part be seen as a way of safeguarding those embryos that have to be created and, potentially, discarded if they test positive for the condition in question. Indeed, embryo discard was an issue of distinct concern to many of those working in the field, as the following discussion shows.

b. ‘Respect’ for the Embryo—Concerns about Embryo Discard

It would be misleading to suggest that all those working in the field are necessarily concerned about embryo discard or donation to research. Rather, for those for whom the embryo has no special status, this was not seen as problematic. For instance, Scientist 8 (Study 1) thought it was ‘absolutely fine to discard embryos’ because they have no central nervous system, feeling of pain, consciousness, concept of their own identity, or any interest in their own future existence’; and Counsellor 17 (Study 1) saw embryos as a ‘ball of cells with no soul, no being, and not in an environment where they’re going to grow and develop into a pregnancy, so research on embryos is something that I have no problem with at all’.

As regards ‘affected’ embryos (those that have tested positive for a serious genetic condition), the view was also expressed that the destruction of embryos should be seen as ‘balanced’ with the goal of PGD, as shown in Doctor 24’s (Study 1) comment: ‘[I]n a way it is killing... but we are fine balancing it to the bigger social requirements... the end result of why we are doing it, for me is justification by itself’.

However, other staff described how they were troubled in various ways by embryo discard, a perspective that is rarely noted. Scientist 2 (Study 1) referred to ‘throwing away potential people’ and having to decide ‘how to deal with it because I’m actually killing something’. Nurse 4 (Study 1), whose work did not entail handling embryos, said s/he ‘couldn’t be an embryologist because... they have to get rid of the embryos that are not used... that would be my problem’. Embryologist 7 (Study 1) reported feeling ‘quite sad’ about disposing of stored embryos ‘because of death... such a waste of embryos, producing, freezing and discarding them, and treating them as something that’s for disposal’. Embryologist 26 (Study 1) described how discarding ‘beautiful’ embryos ‘is actually quite painful’.

26 Another concern might be a worry about the reasons for which possible people should be selected.
An important point that emerged through our research both in the IVF and PGD contexts concerned what one might call the ‘scarcity value’ of embryos: unfortunately, not all embryos have good potential to implant successfully and to make it into the world as born children; and not all embryos have the potential to be born as ‘healthy’ children. In both our studies, staff emphasised the fact that most embryos do not in fact develop into successful pregnancies. For this reason, the idea that couples or embryologists have the ‘luxury’ of being able to select between a range of embryos does not in fact reflect the clinical realities. This of course has implications for the future scope of PGD, a technique that is often viewed with suspicion and hostility, in discussions that might use the misleading term ‘designer baby’. In the light of the ‘scarcity value’ of embryos, coupled with the importance of the criterion of ‘seriousness’, we think it is inappropriate and unhelpful to view the work of those we interviewed as destructive per se, a characterisation made quite vocally, and potentially quite harmfully, in some quarters.27

Other aspects of the work of those we interviewed further show a concern to avoid embryo discard wherever possible. In part, this can be seen in relation to the question of choosing embryos for transfer and the information, for instance relating to carrier status, that might be given to enable choices between embryos. Some staff were not comfortable with the idea of disclosing information, and thereby giving couples the option not to choose embryos that were carriers of a genetic condition that had been the subject of testing, rather than embryos that would develop into people with a serious genetic condition. Staff’s possible discomfort about this was evident in the following EDG exchange (Study 1):

Counsellor 28: You give people a choice?
Scientist 2: Yes.
Counsellor 28: I didn’t know you did that, I have to say.
Scientist 8: I didn’t know that.
Counsellor 28: I feel that’s, I feel very uncomfortable with that, very uncomfortable. I didn’t know you did it.

For instance by Josephine Quintavalle who, together with Margaret Nolan, founded ‘Comment on Reproductive Ethics’ (‘CORE’) in 1994. This is a ‘public interest group focusing on ethical dilemmas surrounding human reproduction, particularly the new technologies of assisted conception’, as stated in the ‘About’ section of the CORE website <http://corethics.org> accessed 21 November 2011. Quintavalle brought the case of The Queen on the Application of Quintavalle v Human Fertilisation and Embryology Authority, the ‘saviour sibling’ case [2003] EWCA Civ 667 (CA); [2005] 2 All ER 555 (HL).
Scientist 2 later explains that the reason why PGD patients might be told of the carrier status of embryos is ‘[b]ecause we have to give them the risks...you have to give them the risks associated with each of those embryos...And we say, “From our point of view, we would prefer to put this one back because it’s got the lowest chance of misdiagnosis...but this one’s a carrier”’.

The issue of sex selection is also pertinent here. Although sex selection per se is not legal, our interviews and discussions revealed worries about information regarding the embryo’s sex being used by couples to make choices between embryos.28 We found that by the way they presented information, staff sometimes have a subtle role in ‘framing choices’ for prospective parents. For instance, an emphasis might be placed on the view that successful pregnancy and the birth of a healthy child are more important than the birth of a child of a particular sex. This might be seen as a way of trying to support women and couples in making choices, while hoping that those choices will not in fact conflict with professional values.29

At the same time, staff were sometimes concerned about whether or to what extent they should withhold information, a stance thought to be in tension with the ethos of giving full information to prospective parents.30 There were also possible unintended consequences of adopting this strategy, as demonstrated in an account given by a scientist in Study 1. Making a comparison with withholding information at the stage of embryo transfer after PGD, s/he recalled an occasion when—in the context of prenatal diagnosis—the strategy of withholding information all went ‘horribly wrong’ and a woman for whom the birth of a boy was very important later inadvertently terminated a male fetus, fearing it was female.31 In this kind of scenario, we suggest, staff are forced to weigh up a range of ethical, professional, and legal considerations relating to the value of the embryo on the one hand and of the developing fetus on the other, along with the need to respect and safeguard women’s (and couple’s) interests.

This brings us to the point that, in general, PGD and possible embryo discard were typically seen as the ‘lesser of two evils’ compared with termination of an established pregnancy.32 Perhaps this is not surprising given staff awareness of the limited potentiality of most embryos, as

28 We discuss this further in K Ehrich and others, ‘Choosing Embryos: Ethical Complexity and Relational Autonomy in Staff Accounts of PGD’ (2007) 29/7 Sociology of Health & Illness 1091, 1098.
29 Ibid, 1101.
30 Ibid, 1099.
31 Ibid.
32 We discuss this further in K Ehrich and others, ‘Testing the Embryo, Testing the Fetus’ (2007) 2/4 Clinical Ethics 181, 184.
noted above. In part, we note this as an empirical claim. For instance, health professionals and scientists working in PGD are acutely aware of how distressing and painful termination of an affected pregnancy may be to a couple, as well as to those involved. In this connection, a scientist in Study 1 observed: ‘Termination at any point is distressing for any person to decide and go through, but also for professional staff involved, and the later it is, the more distressing.’ And in part we note this as a moral claim. For instance, the fetus in an established pregnancy may be thought by some to have greater moral significance than the not-yet-transferred or implanted embryo. It should also be noted that the empirical claim regarding distress is not necessarily discrete from the moral one regarding status, in that one reason for greater distress may relate to the moral evaluations in either case. Both these points are perhaps reflected in what Doctor 24 (Study 1) observed about a couple seeking PGD for Cystic Fibrosis:

We saw a couple last week who came for Cystic Fibrosis, a fertile, intelligent couple, who have a Cystic Fibrosis child. And I said, ‘What are you doing this for? Why don’t you just have another pregnancy?’ And they couldn’t consider terminating a Cystic child because, firstly they said, ‘we do not want to have another child that I have to watch die or be very ill. But on the other hand, if we kind of [terminate the] pregnancy it’s like terminating [our existing child] … And we feel we can’t do that. And we want some other way of approaching this.

In the final section, we reflect briefly on the journey that some embryos may make from the clinic to the laboratory, for the purposes of embryo research.

3. Embryo as Scientific ‘Tool’
Turning to the scientists in the stem cell labs, one might imagine that they would be more inclined to the ‘ball of cells’ account of the embryo. Indeed, we did meet some who were more morally exercised by the work they had conducted on sentient animals than by what they were currently doing with human embryos. Most were comfortable with the embryo’s use in promoting a good from which it will never benefit and which will entail its destruction. However, some were very clear that they understood that the ethical meaning of the embryo as constructed in the clinic remained with it when it made its journey to the laboratory.

If the use of the embryo is transferred over to scientists, it is because it has been defined as ‘spare’ by those who created it for reproductive purposes. In the case of a healthy embryo, it could be spare because its relatively low quality means it was not chosen for transfer or freezing,
because it is surplus to requirements since the couple’s reproductive goals have been achieved, because a couple cannot afford to hold on to it by freezing it (in which case it might be let go with regret) or because the statutory storage time limit (now 10 years) has expired.\(^{33}\)

In the case of an embryo which has been tested and found to be affected by a genetically inherited disease, it is now spare because it will never become the healthy child its biological parents are striving for.

We were greatly struck by the fact that participants were typically very cautious about describing any embryo created for treatment purposes as *spare*, and thus potentially available for research. For instance, Embryologist 2 (Study 2) emphasised that the embryos that are given to research by a couple are only ‘spare’ for them ‘after the patient’s use, yes they’re spare at that point technically. So when you’ve got enough heads on pillows or you’ve decided you don’t want any more out of your treatment, then they’re spare embryos.’ In this way, s/he might be thought to be concerned to protect the reproductive interests of parents so that, only if such parents decide not to have further treatment, should remaining embryos be seen as ones which can legitimately pass from the treatment to the research context. At the same time, caution around the definition of an embryo as ‘spare’ could be seen to reflect the importance of the origins of the embryo within a treatment context aimed at the creation of a child.

At the time of our research, two of the three sites we visited in Study 2 had the ability to develop embryos to blastocyst stage, which is becoming increasingly common. This stage is reached on day five or six following fertilisation and embryos will be developed *in vitro* to this stage when there are enough embryos to justify trying to develop them so as to be able to choose the one or more most likely to result in the birth of a child. Clinician 37 referred to this selection process as ‘uncover[ing] embryo potential as much as possible’. Embryologist 34, from a clinic with the facility to develop embryos to blastocyst stage, emphasised ‘why we’ve gone over to keeping the embryos a bit longer, to give them every opportunity we can to show us that they, they are continuing to develop and with good quality’. He/she describes how h/she does his/her ‘best’ to try to ensure the best embryos stay with patients. This was echoed in other views that were expressed.

We were also struck by what one might call an ‘ethical hierarchy’ of the ethical suitability of embryos for research. A number of participants commented that fresh affected PGD embryos were those in relation to which they felt most comfortable seeking consent for research.\(^{34}\)

---

\(^{33}\) HFE Act 1990, s 14(4) as amended by the HFE Act 2008.

\(^{34}\) This was also a finding in SP Wainwright and others, ‘Ethical Boundary-Work in the Embryonic Stem Cell Laboratory’ (2006) 28 Sociology of
this regard, Research Manager 32 observed ‘I think I’m right in saying, the only fresh embryos that are used are PGD embryos’. And Genetics Scientist 33 talked very particularly about the ethical priority of embryos, observing: ‘I’d say the next step down from the acceptable PGD ones will then go to the acceptable being the frozen IVF ones’. These last are those which couples have decided they will not ever use or donate to others. These embryos therefore have no chance of making it into the world as born people. An ethical hierarchy of embryos, in which the first choice for research embryos is affected PGD ones and the next are frozen embryos that will never be used in treatment, could be seen as protecting the embryo’s chance of life as a born person as much as possible, along with parents’ reproductive interests.

IV. CONCLUSIONS

We were fortunate to have conducted our research after Margot had drawn our attention to the way in which a concern with embryos has driven and shaped regulation of assisted reproduction services and embryo research in the UK. We must also acknowledge her role in highlighting the ‘muddle’ around the embryo, and thank her for encouraging us to take account of the fact that many people do think of the embryo as having an important symbolic value, and therefore regard it as ‘special’.

In this paper, we have tried to show that this holds true, not only for those who may be opposed to embryo research, or at least share the concerns that Margot has so eloquently expressed, but also for those whose work involves them directly in the creation, manipulation, and potentially the destruction of human embryos. We would also like to reassure Margot that even when these individuals do not consider embryos to be special, they are typically aware of the range of views that might be held, not only by those seeking treatment services but also by other colleagues. Overall, we found nothing to suggest that the embryo’s chance of life—where it genuinely has one—is not recognised as something of very great value.

Health & Illness 732. This aspect of our research is discussed in more detail in work by R Scott and others, to be published later in 2012 in this journal.