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Testing the embryo, testing the fetus

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Abstract

This paper stems from an ethnographic, multidisciplinary study that explored the views and experiences of practitioners and scientists on social, ethical and clinical dilemmas encountered when working in the area of PGD for serious genetic disorders. We focus here on staff perceptions and experiences of working with embryos and helping women/couples to make choices that will result in selecting embryos for transfer and disposal of 'affected' embryos, compared to the termination of affected pregnancies following PND. Analysis and discussion of our data led us to consider the possible advantages of PGD and whether a gradualist account of the embryo's and fetus's moral status can account for all of these, particularly since a gradualist account concentrates on the significance of time (developmental stage) and makes no comment as to the significance of place (in-vitro, in-utero).

Keywords

preimplantation genetic diagnosis; in-vitro fertilisation; prenatal diagnosis; embryo; gradualism

Introduction

In the UK, the Human Fertilisation and Embryology Authority (HFEA) is responsible for licensing in vitro fertilisation (IVF) and preimplantation genetic diagnosis (PGD), which is currently used to test for about seventy serious genetic conditions. One of the ethical principles used by the HFEA in approving licences is that indications for the use of PGD should be consistent with, although not necessarily the same as, current practice in the use of prenatal diagnosis (PND). However, the ways in which people understand, value, negotiate and use genetic technologies in relation to PND differ from those in relation to PGD. In particular, clinical and scientific staff make ethically and socially significant distinctions between the disposal of affected embryos and the termination of affected pregnancies.

We have reported elsewhere^{1,2,3} on staff perceptions and experiences of working with embryos and helping women/couples to make choices that will include, in addition to a range of options such as adoption or gamete donation, selecting embryos for transfer and discarding 'affected' embryos. For example, some staff describe three day old embryos as 'a ball of cells' and have few misgivings about their disposal; whilst others view embryos as a form of life and are uncomfortable with the process of allowing those not selected for transfer to perish. For this paper we compared such views with comments staff made

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spontaneously during the interviews regarding the main alternative available to their clients who wish to avoid the birth of children with serious conditions, termination of affected pregnancies following PND. In turn, this led us to reflect on the extent to which a gradualist approach to the embryo's and fetus's moral status, without more, can account for staff's preference for PGD. In essence, a gradualist approach holds that as the embryo and then fetus develops, so does its moral status, so that increasingly serious reasons are needed to justify harm to it. The ensuing discussion we present here responds to the call for multidisciplinary empirical work on bioethical issues^{4,5,6} by incorporating philosophical and social science interpretations. It also contributes to wider debates about how new genetic developments and technologies, and related clinical and social practices, may reflect changes in conceptions of the moral status of embryos and possibly the fetus.

Clinical background

There are important distinctions between the techniques of PND and PGD that we highlight here to explain why PGD offers new opportunities and raises unprecedented ethical and social issues. PND is offered *in pregnancy*, most commonly following routine screening to detect unforeseen fetal anomalies, for example Down Syndrome, and also in cases where women/couples are known to be at substantial risk of having a child who is seriously impaired. This allows women/couples either to prepare for the birth and subsequent care of the child or arrange for a termination of the pregnancy.

PGD offers women/couples who are at risk of having a child with a serious genetic condition the alternative option of having their embryos tested *before implantation and therefore pregnancy* with the aim of avoiding the implantation of affected embryos. IVF technology is used to create embryos in the laboratory, from which one or two cells can be tested for specific genetic disorders. Unaffected embryos can then be transferred to the woman, where they may successfully implant. Embryos affected by serious genetic disorders are either 'allowed to perish' or donated for research. PGD can also help women/couples who have experienced repeated miscarriage due to chromosome rearrangements such as reciprocal translocation.⁷

It has been argued that one of the key advantages of PGD is that it allows women/couples to avoid repeated termination of pregnancies following prenatal diagnosis of genetic disease, which may have serious and long-term effects on women/couples^{8,9}. However, the possible social and ethical implications for *staff* (rather than clients) in the UK of being able to offer PGD as an alternative to PND have not to our knowledge been reported.

Study background and methods

This paper stems from an ethnographic study that explored what actual and potential ethical, social, clinical and legal dilemmas genetic developments and new reproductive technologies pose for practitioners, scientists, policy makers and others working in the area of PGD. Following Ethics Committee approval, the study included observation, interviews and ethics discussion groups with staff from two Assisted Conception Units (ACU) offering PGD and IVF in the UK. Staff disciplines included nursing, obstetrics and gynaecology, radiography, embryology, molecular and cyto-genetics, and administration. As a multidisciplinary team comprised of three social scientists, a moral philosopher, an expert in ethics and law, and a clinician, we explored the social processes, meanings and institutions that frame and produce 'ethics' and 'ethical problems' in this clinical setting. There are several reports on the experiences and views of women/couples undergoing PGD and/or IVF^{9,10,11,12}, and a growing national and international social science and ethics literature on

PGD^{13,14,15,16,17}. This paper adds to the more limited body of in-depth research on the views of staff and policy makers in the UK^{1,2,3,18}.

The project focused on two Assisted Conception Units (ACU) in teaching hospitals in England, which offer a mixture of National Health Service (NHS), privately, or 'self funded' NHS treatment. The clinics provide 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.

This paper draws on 41 staff interviews and seven ethics discussion groups from our two study sites (with a total of 52 EDG participants) generated between May and December 2005, and March and July 2006. Participants were recruited following explanations of the research and informal follow-up approaches from the researchers, and included staff from each of the disciplines working in the clinic. The interviews were conducted as 'guided conversations'¹⁹, lasting between one and two hours. Open-ended questions and an informal interview schedule were used, with topics such as the status of the embryo; views on treatment eligibility for PGD; views on determining the 'seriousness' of conditions; the regulation of this area of genetics and reproductive technology; and the opportunities and dilemmas associated with PGD as a new technology. These topics frequently led our research participants spontaneously and then through follow-up probing to consider the advantages and disadvantages of PGD compared to PND.

For our initial analysis of the transcripts we used a modified version of the framework approach²⁰, generating topics such as differences and similarities between PGD and PND; termination of pregnancies following detection of anomalies; and allowing embryos to perish. Further examination of this data by a social scientist (KE) and moral philosopher (BF) stimulated our thinking and led to a discussion between us beginning with an initial consideration of philosophical approaches that might capture the views of staff, and then more specifically focusing on the gradualist account. This focus arose from the data suggesting to us that although many practitioners in this field in general might be assumed to be in alignment with that account, aspects of PGD and our data appear to raise novel and pertinent questions regarding the extent to which gradualism by itself represents the beliefs of staff about PGD compared with PND. We also consider some additional elements of staff views which the gradualist account, as a normative theory, does not address.

We formulated this line of enquiry post data collection and therefore did not ask participants specifically about new ways of thinking about gradualist accounts. The discussion we present here arises from the further analysis of our data from our philosophical and social science perspectives, and therefore we include only brief illustrative quotes. In particular, we consider how the technology of PGD highlights a distinction between the significance of time (developmental stage) and place (in-vitro, in-utero).

The philosophical debate

To begin, we present a summary of the philosophical debate about the moral status of the embryo and fetus that we used as our embarkation point. For as long as most commentators can remember, there has been a debate within moral philosophy about at what point (if any) human life (*per se*) becomes morally significant. This issue has replaced the more traditional enquiry into 'when human life begins', a question now taken by philosophers to be essentially biological as opposed to ethical.

In a sense this debate is irresolvable, but a major point in the discussion is that different groups and individuals place value in life at different stages of development and for different reasons. Such is the recognition of this diversity and potential for disagreement that Mary

Warnock notably announced in her 1984 report that ‘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 judgements. Instead of answering these questions directly we have gone straight to the question of *how it is right to treat the human embryo*’ (DHSS 11.9 p. 60)21.

In this paper we are concerned with understanding how individual practitioners’ views on how to treat embryos and fetuses might be influenced by their views on the more fundamental moral issues relating to the status of human life at the various stages discussed, together with some additional elements from their responses.

Gradualism and developing status

When considering the moral value of human life, amongst the most conservative moral positions one might encounter is the belief that human life becomes morally significant at conception, and the level of significance is such that it bestows an inalienable and absolute right to life. Another conservative position adopted in this context invokes the concept of ‘potentiality’ in support of the early moral significance of human life. That is the idea that once a human life has been created it has the potential to develop to full personhood, and therefore there is a moral imperative upon us not to interrupt or jeopardise that potential development even in its earliest stages.

Staff at the clinics deal with the creation and possible destruction of human embryos. For this reason, one might not predict that a moral concern for the embryo might be represented amongst our interviewees. However, many practitioners within this field bestow some moral significance (of apparently varying degrees) at the early stages of development. This means that they expect the embryo to be treated with particular care and respect, even if it will ultimately be destroyed^{3,22}. (Such views may in fact be more easily compatible with a gradualist account of the embryo’s status, rather than a conservative position which grants full moral status, with all that that implies, to the embryo.)

If one rejects the conservative positions that emphasise the moral significance of the mere presence of human life and/or the potentiality for personhood, one then has to ask what would or could make the moral difference in affording full moral status and consequent protections, and again there are a variety of views. Traditionally some cultures and religions have placed importance upon the experience of quickening, the point at which a woman first experiences the feeling of the fetus within her womb. Moving on from this relatively early stage (16 to 20 weeks), others have argued that the point at which human life becomes viable without the biological support of a woman’s body is the point at which the fetus should be considered to have an independent right to life.

In some ways, these arguments might be thought to be compatible with a gradualist approach to the fetus’s moral status. As the embryo becomes a fetus, and matures towards viability and independence, its status grows. That said, an argument based on fetal viability is not, strictly speaking, a gradualist one, since it necessarily hinges on the idea of fetal rights, which a gradualist argument does not, and since it assumes that prior to fetal viability the fetus can have no moral claims, again contrary to a gradualist account *per se*.

One might also explore the transition from fetus to neonate, but interestingly in recent years we have moved away from the idea of birth as a morally significant marker. Within philosophical as opposed to psychological or sociological discourse, the moral significance of the fact that a fetus has been delivered from a woman’s body is sometimes considered hard to defend. It may have huge psychological force, but in moral terms it is considered difficult to see a morally relevant difference between a full-term fetus two days before birth

and the same fetus, now a baby, immediately after birth. These factors have been interpreted by some philosophers as implying that the *place* in which a fetus exists, i.e. in the woman's body, is not significant to its status²³. Rather, the developmental dimension takes priority over place when formulating a view of moral significance. For others, however, the fetus's place within the woman's body is highly relevant to the question of its moral claims²⁴.

Despite the difficulties that arise when trying to pinpoint stages along the early developmental schedule of human life when life becomes more significant, there is a clear strand of gradualism within the broader assisted reproduction and abortion debates. Stronger protections are expected for more developed embryos and fetuses and stronger moral justifications are required for the destruction of life the further it develops.

Although the staff who participated in our research did not often express their views on these issues in philosophical language, we considered this a useful starting point from which to analyse their views. We acknowledge that although participants' accounts may contain both psychological responses and indications of their beliefs and moral principles, these may not always be compatible. Moreover, it is important to distinguish between the two since people frequently hold beliefs that are not consistent with their psychological responses. At the same time, we wish to contribute to the engagement of social science with bioethics by trying to capture the use of 'concepts embodied in specific acts and orientations within the framework of a situation'²⁵. An important aspect of this endeavour is to consider how categories and assumptions contained in ethical theory such as those outlined above may either correspond or conflict with descriptions of particular embodied orientations⁶. Therefore this paper is situated within an iterative analysis of our data drawing on a set of philosophical theories, and then posing questions from a social-science perspective. To be clear, we are not proposing a critique of gradualism or suggesting that all of our participants would wholly accept or reject it as a normative position. We are interested in practitioners' views about testing (and disposing of some) embryos, which led many participants to make comparisons to termination of pregnancies following PND. We have found it useful to explore these views in relation to gradualism but we acknowledge that gradualism as a normative theory does not itself claim to account for how people actually behave or feel about these issues.

Comparing PGD to PND for serious genetic conditions

There were several areas of questioning in our interviews that tended to produce spontaneous comparisons between PGD and PND. Some of these were the topic of the moral status of the embryo; the general question of what opportunities PGD offered to women/couples; and when interview participants gave reasons for their motivation for working in PGD that depended on a comparison with PND.

Practitioners' own aversion to destroying 'life'

As in previous projects^{26,27} and in the current study reported elsewhere^{1,2,3}, we did not find strong versions of the absolutist approach to the full moral status of the embryo or termination of pregnancy within our cohort. However, some staff were troubled in connection both with questions about the status of the embryo and by the opportunities PGD offers. Some practitioners had to find ways to reconcile their feelings about the destruction of embryos entailed by PGD with their own belief system. For others, the avoidance of direct participation in terminations following PND was of primary importance. One member of staff said that compared to PND, PGD was 'the lesser of two evils', and others said that they disliked terminations for any reason.

These views expressed by staff may in some cases be influenced by the feelings of distress they attributed to women/couples facing the possibility of termination. However, it was clear that for some staff, the idea of later termination of pregnancy was experienced as more distressing *on their own behalf* than the disposal of an affected embryo. As an illustrative quote, one participant said:

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.
(Scientist)

This comment refers to distress associated with termination increasing ‘the later it is’, and could indicate both beliefs about moral significance accruing with developmental stage and a dislike of termination of pregnancy when seen in the context of comparison to disposal of embryos following PGD. A factor of relevance here is the difference between the practices associated with terminating a pregnancy and destroying a fetus, and disposing of an *in vitro* embryo. Our interviews did not focus on the former since most staff were not engaged in these practices, but we have some data about the latter. For example, one embryologist described in detail what is meant by ‘allowing the embryo to perish’, a phrase frequently used by staff to describe the process whereby embryos that will not be transferred to the woman’s uterus, stored in a frozen state, or used for research, are exposed to conditions that will not support life. These embryos have failed to develop at a rate regarded as signifying likely implantation success, or have tested positive for a serious genetic condition. The phrase ‘allowed to perish’ may seem to gloss over possible moral objections and/or emotional responses to the destruction of embryos, and in some ways also the difficult decisions behind the selection of embryos, and we address these topics in more depth elsewhere^{2,3}.

Further factors indicated in our broader data set may be equally important. For example, some practitioners’ professional route into the ACU was motivated by the wish to help couples create life, and they see their primary calling to work in IVF rather than PGD. Practitioners might have a problem with discarding embryos if their priority is the creation of life in challenging circumstances as opposed to the avoidance of particular conditions or diseases, and it is worth noting in this context that many couples who undergo PGD are not infertile. These factors could contribute to practitioners’ aversion to termination of pregnancy after PND on their own behalf apart from beliefs and feelings about how women/couples may be affected.

Empathy for the difficulties women/couples face in relation to PND

Most of the staff in our study shared the view that women/couples should if possible be spared the experience of terminating a pregnancy. Closely associated with this was the belief that PGD allows women/couples at increased risk of affected pregnancies the welcome option of testing for serious genetic conditions before pregnancy, thereby reducing the likelihood of having to consider termination of established pregnancies. They believed that this new option allowed many women/couples to consider PGD who could not contemplate having PND and terminating an affected fetus: indeed this is one of the reasons commonly given during initial consultations for requesting PGD. For some staff, termination of pregnancy for any reason was seen as ‘painful’, ‘horrible’, or ‘traumatic’ for women/couples. PGD therefore offered their clients a form of ‘rescue’ from having to make ‘appalling decisions’.

The specific issue of distress to women/couples in relation to PND and termination of pregnancy has been assumed to borrow from the gradualist account of the growing moral status of the embryo/fetus. That is, as the fetus develops and becomes more recognisably human its destruction becomes more distressing for all concerned, including possibly the

fetus itself^{28,29}. As a further link to the gradualist account, PGD was thought to be preferable to PND because it was seen as much harder for women/couples to make a decision to terminate half way through pregnancy than not to select a three-day-old embryo.

It is worth considering the importance of the moral significance of developmental stage as claimed in the gradualist account alongside other potentially important factors. The invasive nature of pregnancy termination, the biographical disruption that ensues from ending of the woman's established pregnant state and status, and the anxiety engendered by the uncertainties involved in PND once the woman is actually pregnant may be equally important to staff as the significance of developmental stage. Getz and Kirkengen³⁰ discuss a number of ways in which women have been harmed by such experiences arising from routine fetal screening, and one of our study participants recalled how his perception changed regarding the decision women/couples face when PND tests indicate, for example, an estimated 1:200 risk of an affected pregnancy, when he and his wife were in this situation themselves:

Actually putting myself in that position of the patient, it completely changed my perspective - since we'd been giving risk figures out to people subsequently in the way that we do, because I can imagine what it's like getting that figure, that result myself now. (Scientist)

A further significant factor indicated in our study was that many women/couples are averse to terminations of affected pregnancies at any stage of development for religious reasons, although different religions can also distinguish between the moral status of the embryo and the implanted fetus. This range of views was also reflected in the comments of some of the staff who participated in our study.

The significance of place and time in relation to gradualism

As we have seen above, many of our research participants' views when comparing PGD and PND may be influenced by their beliefs about the woman/couple's wishes when expressing a preference for PGD. To a large degree it might be assumed from the gradualist approach that such views are determined only by a belief that the moral status of the embryo increases as it develops into a fetus. However, we have also considered some further reasons which are not addressed by the gradualist account, given its focus on the growing moral claims of the embryo and fetus. In effect, we suggest that there are other important issues at stake in the comparison of PGD and PND, beyond the question of the justification of harm to the embryo or fetus with which a gradualist account is necessarily concerned. Thinking about these possible alternative reasons as to why termination is perceived as distressing both to staff and to women/couples led us to attribute significance to other factors, beyond the issue of developmental stage in the gradualist account, and to focus on important potential differences that the new technology of PGD introduces.

In the following illustrative quotes, morally relevant contrasts are drawn between an embryo in a dish and a fetus in a womb, both in terms of *place*, and in terms of *time*:

I don't think an embryo as such, outside of the body, is as precious as a fetus growing inside a womb... I would give less rights to an embryo outside of the body than I would to a fetus. (Counsellor)

Yes, a lot of people actually would go for PGD, who probably would not have gone for PND because of the timing thing. You are still going to be in the first trimester of the pregnancy when you're going for tests, which, for a lot of people, it won't be acceptable because I mean, I myself haven't been pregnant, but I would imagine, once you know that you're pregnant, then any kind of having to make decisions about termination must be very destroying on you, so yes. Because you're actually

making a decision for these embryos that are not even in utero, they're not inside you yet. So that would be, I think, then a very different sort of conscious decision that people would be making then. (Scientist)

These comments are interesting because they highlight the significance of place and time in a different way to previous arguments that concentrate on distinctions between the rights of the unborn fetus and newly born child in a developmental logic, that is, the fetus inside *and then* the baby outside of the woman's body following birth. The significance of place is highlighted because the technology of IVF and PGD allows for the consideration of women's/couples' wishes and the possible moral claims of the embryo *before* the embryo has been placed in the woman's body.

As Pfeffer and Kent³¹ and Franklin and Roberts¹⁸ have pointed out, in some ways embryos are better protected, accounted for and regulated in English law than fetuses, and there are some legal differences worth pointing out. One is that unlike the embryo in the laboratory, the legal status of the fetus *in utero* is as part of the mother's tissue. Another is that although PGD and termination of pregnancy following PND are both carried out on the grounds of substantial risk of a serious condition, the latter requires legally sanctioned justification while the decision not to implant particular embryos does not^{32,33}. These legal differences can be considered in relation to early (pre-1990s) feminist criticisms of new reproductive technologies that noted an ideological wedge being driven between the pregnant woman and her fetus, with the fetus increasingly being seen as separate and distinct from the woman's body, interpreted by some writers as "an assault on the bodily integrity, right to choose, and privacy of women"³⁴. Later feminist studies focused on the social construction of the meanings and significance of the fetus³⁵, including a recognition of the social life and status of fetuses and ways in which this interacts with women's procreative agency³⁶. Some critiques associated the separation of fetal and women's interests with a medical model oriented primarily in the production of a healthy baby so that all other interests are secondary to 'fetal outcome'³⁷. While we cannot discuss the implications of these different views on the relationship between embryos and the significance of the woman's body in depth here for reasons of space, these points briefly indicate the importance of place and embodiment in the wider debates.

Getz and Kirkengen³⁰ argue we should discuss wanted pregnancies 'in terms of *one existential nucleus* - the most basic, developmentally dynamic and vulnerable of all human relations' (p2053). In the related context of the potentiality argument used in the debate about which embryos can be considered morally eligible for embryonic stem cell research, Agar³⁸ proposes an argument 'for the pragmatic superiority of a principle that distinguishes embryos in terms of the presence or absence of a functional relationship with a womb' (p. 199). He also proposes an emphasis on the moral significance of the woman whose womb is involved, even if there may be doubt as to *when* embryos in women's wombs become morally significant.

These reflections lead us to place an emphasis on the significance of the *place* of the embryo in IVF with PGD, a point regarding which a gradualist account, without more, is not concerned. (Arguably, however, a gradualist account is not incompatible with this reflection, and more generally, a gradualist account has no reason to be "threatened", as it were, by an emphasis on the significance of the place of the embryo *ex utero*, since by itself it makes no comment about this.)

Discussion

We have considered staff views on two genetic and reproductive technologies, PND and PGD, and a number of reasons why as a group the staff in our study tend to regard PGD as a

good option - clinically, socially and ethically - to be able to offer women/couples, not only in their clients' interests but also in some ways their own.

One strand of their arguments relates to the moral significance of the embryo as compared to the fetus. While elements of a gradualist approach were recognisable in many of the interviewee's comments, we have also considered interesting additional factors from the broader data set. These include views of some staff about the moral status of the embryo that are sufficiently conservative to suggest that they may consider 'conscientious objection'³⁹ to certain practices; and professional routes into the ACU that provide staff with motivation based on the creation of life in challenging circumstances rather than the prevention of life affected by serious conditions.

The comments considered in this paper can be understood in terms of how the embryo and fetus are (socially and ethically) constructed in different ways because of the new context that PGD presents. Transformations of moral significance occur through the processes used to test, foster and transform embryos/fetuses at different times and places.

The embryo created as part of PGD treatment is transformed from the product of IVF into an entity that is only ever going to be transferred for possible implantation once there is sufficient confidence that it will be unaffected by a serious disorder. Although the process cannot produce 100% certainty, the embryo is created outside of the woman's body so that it may be tested, and has only a 'provisional' existence and future. If it 'fails' the test it will be allowed to perish or donated for research and ultimately destroyed.

By contrast, a fetus implanted in the woman's womb already has an existing relationship (albeit perhaps a tentative one⁴⁰) with the woman/couple as 'a pregnancy'. Although the social construction of a fetus can be transformed in a number of possible ways through PND, it exists *inside* the body. Its place within the woman's uterus distinguishes it from an entity constituted in the context of the testing technology to one constituted as a pregnancy. Thus the fetus can be understood to 'belong' physically, socially and in other senses to the woman/couple in a morally significant way because of its place in the woman's body. It is literally an 'insider', whether it does or does not have a future. Its removal entails a procedure that most people perceive as distressing, and this may increase over time. In this light, we suggest that there are other significant factors involved when staff compare PGD and PND that are not necessarily addressed by the gradualist approach by itself, since this approach is concerned with the question of whether harm to the embryo or fetus can be morally justified. The intrusiveness and invasiveness of the procedure, its biographically and physically disruptive nature, and different religious understandings about the beginning of life are just some of the factors that may be experienced as equally significant to women/couples and may therefore be important values in staff empathy and their feelings about these matters on their own account.

We suggest further that these differences between PGD and PND could be significant, even if there were hypothetically no difference in the length of time embryos/fetuses in each case had existed. Testing of the embryo before it exists as part of a pregnancy or even a potential pregnancy inside the woman's body highlights the importance of *place* as well as time.

We have highlighted important *additional* dimensions at stake, beyond the question of the growing moral status of the embryo or fetus with which a gradualist account, without more, is necessarily concerned. Comparison of some of the harms and benefits of the two procedures and the moral significance of the place of embryos in vitro, compared with the fetus in vivo, raises new ethical issues for staff.

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