
Choosing embryos: ethical complexity and relational autonomy in staff accounts of PGD

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Abstract The technique of preimplantation genetic diagnosis (PGD) is commonly explained as a way of checking the genes of embryos produced by IVF for serious genetic diseases. However, complex accounts of this technique emerged during ethics discussion groups held for PGD staff. These form part of a study exploring the social processes, meanings and institutions that frame and produce 'ethical problems' for practitioners, scientists and others working in the specialty of PGD in the UK. Two 'grey areas' raised by staff are discussed in terms of how far staff are, or in the future may be, able to support autonomous choices of women/couples: accepting 'carrier' embryos within the goal of creating a 'healthy' child; and sex selection of embryos for social reasons. These grey areas challenged the staff's resolve to offer individual informed choice, in the face of their awareness of possible collective social effects that might ensue from individual choices. We therefore argue that these new forms of choice pose a challenge to conventional models of individual autonomy used in UK genetic and reproductive counselling, and that 'relational autonomy' may be a more suitable ethical model to describe the ethical principles being drawn on by staff working in this area.

Keywords: genetics, choice, ethics, PGD, relational autonomy

Introduction

The technique of preimplantation genetic diagnosis (PGD) is commonly explained, for example, as:

'A way of checking the genes of three-day-old embryos produced by IVF for serious genetic diseases . . . In the laboratory, one or two cells are extracted from the embryo and are examined for specific genetic faults' (HFEA 2005: 34).

In this paper we explore the social and ethical implications for staff arising from the more complicated accounts of this technique given by practitioners, scientists and others working in PGD in the UK. We wish to make clear from the outset that the model of individual autonomy referred to here is based on a particular view of ethics, and dependent on the medical and wider cultural, historical and legal context in which it occurs, and as such would clearly differ from those in other countries. Specifically, we focus on staff views about the part that women/couples play in deciding which embryo(s) to replace in PGD, where the goal is to have a particular kind of baby, that is, not simply 'a' baby, but a 'healthy baby'. This presents novel dilemmas compared to those commonly raised in relation to in vitro fertilisation (IVF) or prenatal diagnosis (PND), and arguably puts women/couples in an unprecedented position in relation to reproductive technology, in 'an arena where medicine, social values and culturally determined meaning are closely intertwined' (Getz and Kirkengen 2003: 2054). In IVF procedures, embryos for implantation are selected by embryologists, but, as will be explained in more detail later, PGD potentially offers women/couples the opportunity to play a greater role in selecting the embryos to be transferred. With PND, women/couples can use the information from tests to choose whether or not to *continue* a pregnancy; but following PGD, women/couples can decide which embryos (if any) to have transferred for implantation *before* becoming pregnant. We sought the views of staff about the social and ethical dilemmas these situations might raise, and how they see their own participation in facilitating and framing these choices.

We report on two sets of dilemmas highlighted by staff as representing social and ethical 'grey areas' which have opened up since the introduction of PGD. The first concerns the ultimate goal of PGD to achieve a 'healthy baby'. The issue here is whether this goal should include accepting embryos with a 'carrier' test result. These embryos would not usually be expected to develop into children with significant symptoms themselves, but the children could potentially pass on the relevant genes to their own offspring. Thus, selecting only completely unaffected embryos and not carriers could be seen as extending the goals of PGD beyond the health of the immediate child in question. The second set of dilemmas concerns choosing the sex of embryos for social reasons. Although this is currently illegal in the UK, the Human Fertilisation and Embryology Act 1990 is under review and this issue is subject to much debate. Part of the remit of our project is to explore potential dilemmas that might occur, ahead of time, so that staff have time to think about the issues, and to inform policy makers about their views of possible developments. In addition, although laboratory procedures make information about the sex of embryos available in specific cases such as where a condition is sex linked, technological advances mean that this information is likely to become increasingly available and therefore women/couples could potentially take this knowledge into consideration when making choices.

We argue that these new possibilities for women/couples using reproductive technologies for genetic reasons pose a challenge to conventional models of autonomy used in genetic and reproductive counselling. Attempts to accommodate unprecedented types of decision-making within an ethos of informed choice and non-directive counselling may create problems as much for staff as for women and their partners (Williams, Alderson and Farsides 2002a). In presenting the views and experiences of staff who are involved in offering women/couples these choices, we build on the findings of Farsides, Williams and Alderson (2005), that practitioners working in the closely related field of antenatal care do not necessarily hold homogenous moral views; and Williams' (2006) discussion of practitioners' complex efforts to 'manage' new types of medical uncertainty. This paper therefore offers a contribution to the growing number of sociological and anthropological studies

exploring the ways in which ethical dilemmas and reflection occur in the clinical situation (Haines 2002, Hedgcock 2004).

Clinical background

There are important distinctions between the associated techniques of IVF and PGD that we highlight here to explain why PGD raises unprecedented ethical and social issues. PGD is offered to women/couples who are at risk of having a child with a serious genetic condition, although The Human Fertilisation and Embryology Authority (HFEA) has recently widened the scope for PGD, to include susceptibility to later onset cancer conditions such as inherited breast cancer. PGD can also help women/couples who have experienced repeated miscarriage due to chromosome rearrangements such as reciprocal translocation (Braude *et al.* 2002). One of the key advantages of PGD is to avoid repeated termination of pregnancies following antenatal diagnosis of genetic disease, which may have serious and long-term effects on women/couples (Lavery *et al.* 2002). The live birth rate for IVF varies according to factors including the age of women and whether the embryos used are fresh or frozen. Clinics claim success rates ranging from less than 10 per cent for women over 40, up to 59 per cent for women below 35 (HFEA 2005), with a commonly cited average rate of between 20–25 per cent. Success rates for PGD are often lower, because genetic diagnosis excludes embryos for transfer.

The goal of IVF is to assist women/couples to achieve pregnancy, and embryologists make decisions about which embryos to transfer based on established criteria for the quality of each embryo. This relates to morphological grading, which includes factors such as the clear categorisation of the rate of cleavage, and size and clarity of individual cells. In contrast, the choice between embryos in PGD involves consideration of many additional factors. After genetic testing, a choice may need to be made between embryos according to a range of diagnostic information, including whether the embryo is a carrier or completely free of the genetic condition. For each embryo a calculation is made for the risk of misdiagnosis. Account is also taken of the way in which disease is inherited and how penetrant the disease is – that is, how certain it is that a person carrying a faulty gene will be affected by the condition.

In PGD, there is the potential for women/couples to play a more central role in selecting (an) embryo(s) for transfer. The main reason is that practitioners and scientists, drawing on complex biomedical and clinical knowledge, present women/couples with information and risk factors for each embryo considered viable. Staff stress that few women/couples have more than two embryos suitable for transfer per PGD cycle, and it would be quite possible that the only viable embryo might be a carrier. The HFEA currently allows two, or exceptionally three, embryos to be transferred after diagnosis, but UK regulations on this are under review and it is likely that because of the dangers of multiple pregnancies and births, only one embryo will be transferred in future. It is therefore possible that the opportunities and dilemmas presented by having to choose between embryos may become more common in PGD in the near future.

Relational autonomy

In the UK, decision-making in this area of reproductive healthcare is usually discussed within an ethical framework of supporting individual choice and the principle of autonomy for women/couples (see for example Soini *et al.* 2006). However, the creation of children

and the selection of embryos implicates staff in ways about which they may feel ambivalent, including dilemmas about the wider social impact of individual choices (Ehrich *et al.* 2006, Brock 2005). Conventional models of autonomy have been criticised for emphasising individual choice, and for paying insufficient attention to wider social contexts in which reproductive technologies both shape and are affected by such choices (Sherwin 1998, Mackenzie and Stoljar 2000).

In a study of lay views on PGD for social sex selection, Scully, Banks and Shakespeare (2006) found that participants were doubtful about the unequivocal benefits of choice in general, and were aware that reproductive choice in particular might be morally problematic. Participants almost universally agreed that the voluntary relinquishment of *control* over such issues as sex selection for social reasons was fundamental to being a 'good parent', even if sex selection by PGD did not in itself present a special harm or advantage to the child. Yet they also agreed that there were limits to the virtue of acceptance, so that selecting an embryo through PGD would be acceptable if the purpose was to avoid having a child with a serious genetic disease or impairment. Participants acknowledged the difficulty in deciding exactly where the transition should be between appropriate relinquishing of control, and an externally regulated ability to choose. They were also highly sensitive as to the processes through which individual moral choices could collectively lead to a 'slippery slope'. Similarly, in Petersen's (2006) study of the experiences of people with genetic conditions and their reproductive options, some participants expressed concerns about possible future offspring, leading them to favour what was fair or right for the child's future, rather than their own desires.

Our study can be seen as complementary to Scully *et al.*'s (2006) and Petersen's (2006) work with lay people and people with genetic conditions, because it provides information on how staff regard similar ethical issues. Importantly, participants in Scully and colleagues' and Petersen's studies demonstrate a form of reasoning that contrasts with the secular-liberal ethical framework common in Western bioethics, in which reproductive choice is seen as an expression of personal liberty and autonomy. Instead, these authors consider the concept of parental self-determination within the model of relational autonomy (Sherwin 1998, Mackenzie and Stoljar 2000), which, 'stresses the *non-individualistic* nature of the moral agent. It depicts the autonomous human as being inescapably constituted through relational networks' (Scully *et al.* 2006: 30, emphasis in the original). In Scully *et al.*'s (2006) study, parents saw voluntary self-limitation of choices as constitutive of the 'good parent's' identity, and felt that parental autonomy was only possible within the limits set up by this framework.

The relational autonomy approach has been developed by feminists, who emphasise that an analysis of the characteristics and capacities of autonomous agents needs to take into account their emotional, embodied, desiring, creative and feeling, as well as rational, nature, within complex social and historical contexts (Mackenzie and Stoljar 2000: 21). Dodds (2000) claims that autonomy has been conceived in much of the bioethics literature as equivalent to informed consent, thus restricting the exercise of autonomy to making choices within a narrow set of options, which have been 'marked out by the institutional framework of healthcare provision, including healthcare resources, [and] medical education . . .' (Dodds 2000: 223). She argues that

'an appropriate, relational approach will attend not just to health-care *choices* but also to the ways in which health-care practices can contribute to the development and shaping of people's capacity for autonomy' (2000: 214).

Donchin (2000) claims more specifically that background norms, practices, social structures, and institutions configure and limit options for *genetic* decision-making, and that the

'self-determining self' is continually remaking itself, in response to changing relationships with others (2000: 239). This emphasises the ongoing nature of relational autonomy as part of a contingent, and continually emergent and accomplished social order (Allen 1997, Casper 1998). Dodds and Donchin are primarily concerned with drawing attention to how socialisation and social relationships within particular historical and social conditions impede or enhance autonomy for reproductive healthcare users.

In this paper, we report on ethically contentious areas which UK staff have raised in relation to the use of a particular model of choice, where the historical and legal context differs from those in other countries. We consider the range of moral positions and problems that working within an ethos of informed, individual choice, as used in the UK, can pose for PGD staff. We pay particular attention to how staff shape information, and configure or frame options for women/couples. We argue that relational autonomy may provide a better model of autonomy for the kinds of decision-making they are engaged in with women/couples choosing embryos following PGD.

Methods

This paper reports on one aspect of an ongoing project which explores the actual *and potential* ethical, social, clinical and legal dilemmas that genetic developments and new reproductive technologies pose for practitioners, scientists, policy makers and others working in the specialty of PGD. We are examining influences on, and interactions between, different disciplines, and exploring the social processes, meanings and institutions that frame and produce 'ethics' and 'ethical problems'. The project uses multiple methods to study two sites (only one of which is drawn upon here), both Assisted Conception Units in teaching hospitals in England which offer a mixture of National Health Service (NHS), private or 'self-funded' NHS treatment. The clinics provide a range of services including IVF and PGD.

Following Ethics Committee approval, the research has included running ethics discussion groups (EDGs) with staff from a range of disciplines including nursing, obstetrics and gynaecology, radiography, embryology, molecular and cyto-genetics, and administration, selected because their work involves contact with women/couples undergoing PGD. The groups were facilitated by a healthcare ethicist (BF), and were of mixed disciplines and seniority. This innovative methodology has been used successfully in two previous studies by two of the authors, BF and CW (Alderson, Farsides and Williams 2002, Wainwright *et al.* in press). The paper draws on five such groups with four to six participants in each (23 participants in total), carried out between October and December 2005. Topics for the groups were generated from a content analysis of 26 interviews previously carried out with individual staff, and by asking interviewees what issues they felt could usefully be discussed in EDGs. Topics identified included views on treatment eligibility for PGD; views about the genetic conditions that should be tested for; and the efficacy of regulatory bodies such as the HFEA. Most of those interviewed participated in an EDG, and some groups included staff who were not interviewed. Groups lasted two hours, and all of the discussions were tape-recorded.

Group transcripts were analysed using a modified version of the framework approach (Ritchie and Spencer 1994). The transcripts were examined for emergent themes. 'Choosing embryos', 'carrier embryos' and 'sex selection' were identified as themes capturing areas in which staff experienced dilemmas, or ethical and social 'grey areas', which have opened up since the introduction of PGD. Sections of the transcripts relating to these themes were then grouped together and analysed further to generate sub-topics. Study numbers are used to protect anonymity, and reference to occupations is in general terms rather than specific job titles.

'Carrier' embryos and the 'healthy child'

In this section we discuss two intertwined themes. The first is the classification of embryos using concepts such as 'healthy', 'unaffected' and 'carrier'. The second theme describes staff attempts to facilitate and frame women's/couples' choices between embryos in these categories, which also relates to the possible wider social effects of testing and choices.

Classification of the embryo

When using the categories of 'healthy child', or 'unaffected' embryo, some staff include embryos with carrier status and assume the acceptability to women/couples of carrier embryos being transferred. According to this view, the goal of helping women/couples have a 'healthy baby' can be achieved because a person can carry disease-linked mutations but not manifest the disease symptoms in their own lifetime. Choosing to replace only embryos that are not carriers could be associated with a 'stronger' (Shakespeare 1998) or 'positive' (Buchanan *et al.* 2000) form of eugenics, because the effect would be to eliminate that genetic anomaly for future generations, as well as the current one.

For women/couples undergoing PGD there may be a conflict between wanting to choose a non-carrier embryo and having a child at all, because so few embryos result in a successful pregnancy. Whilst most staff are keen to ensure that women/couples have a 'healthy' baby (*i.e.* possibly a carrier), some were sympathetic to those who did not want to accept carrier embryos, because they hoped to spare their child from similar dilemmas in their future reproductive life. In the EDGs, some diverse assumptions and practices amongst staff emerged:

- Scientist, 2: . . . we say to them, 'Look you've got a selection of embryos, do you want carriers or do you want normals put back?' Because that's up to the patients ultimately . . .
- Scientist, 8: They'll have a normal baby whatever. So you're giving them the choice.
- Doctor, 22: Do you choose carriers over the normals? I mean do you choose the best embryos?
- Scientist, 2: Yes we look for the best embryo, but sometimes if there's a choice, you've got two good embryos or there are three, and you know, you've got the carriers and the normals . . . but some of them have got an objection to having a carrier child. So we, they, select just the normals to go back, because they don't want a child to have to go through what they've gone through . . . (EDG 2)

This illustrates some differences in the use of classifications and assumptions that may be held by members of staff. Whilst Scientist 2 contrasts 'carrier' embryos with 'normals', Scientist 8 sees the carrier embryo as leading to a 'normal' baby; the doctor's question, however, implies that choosing the 'best' embryo does not necessarily exclude 'carriers'. These classifications are not purely technical, but carry social meanings, as, for example, when Scientist 2 acknowledges that some couples only want to transfer non-carrier embryos because they do not want their child 'to have to go through what they've gone through'. Such distinctions support the finding of Farsides, Williams and Alderson (2005), that in large multidisciplinary teams, it should not be assumed that members hold entirely homogenous views, as indicated here by their different classifications of embryos.

Choice, carrier status and a 'healthy' baby

The language of offering women/couples choice was a key theme throughout the EDGs, but the possibility of allowing women/couples not to accept 'carriers' was evidently not welcomed by some staff:

- 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 (EDG 2).

These comments illustrate the recurrent theme that many staff recognised that such decisions could have potential social implications beyond the immediate family or medical team, thereby emphasising a collective sensibility more in keeping with a relational model of autonomy.

The different practices in IVF and PGD regarding women/couples selecting embryos are highlighted in the following exchange in EDG 5. Embryologist 33 works mainly in IVF, whilst Scientist 2 also works in PGD:

- Embryologist, 33: Why are [PGD] patients picking the embryos? I don't understand, when just normal IVF patients . . .
 Scientist, 2: No, no, but in PGD they have maybe four embryos available and of those maybe two look about right – and if you're lucky you've got three that are potentially implantable. And then, you know, it's up to them, of those three, which ones.
 Embryologist, 33: Why is it up to the patients? . . . Normal IVF patients go through and they show up at transfer and we say, 'These two are the best, they're the ones we're putting back today'.
 Scientist, 2: Because 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'.

This extract illustrates how the goal of achieving a successful pregnancy through IVF is different from the goal in PGD, which is to choose the embryo(s) most likely to develop into a 'healthy' child. It also illustrates how views differed as to how much choice and information should be offered to women/couples. In IVF the choice is a more limited, technical assessment of the viability and quality of the embryo whereas in PGD, the information includes genetic diagnosis, making the choice a more intricate and socially significant one. PGD staff are thus put in the position of giving women/couples technical information and conveying complex knowledge, whilst simultaneously shaping the information in light of the social implications the choice will carry:

- Scientist, 2: Obviously you wouldn't turn round and say, 'Take that one, it's an absolutely horrible looking embryo but it's normal, the rest are all carriers – that's a normal one, but it's not going to get you pregnant' . . . you give them advice and you don't tell them what to do . . . I mean you say the things in a way that, you know, makes it sound like, 'this is the best one.' Obviously in terms of morphology, you say, 'this has got the best chance of

implanting,' but they have to have the other information as well to make their decision. And at the end of the day it's their embryos . . . So if they decide not to have the normals put back and have the carriers, they have to live with the decision that when that child is growing up, that child might have some problems, but it was the one that had the nicest looking embryo . . . They have to live with that decision they make. So you can't just be, 'We think it's this one, you should have this one'.

The social implications of having to consider that the child might have 'problems', and having to live with their decision, are clearly ones the scientist feels should inform the woman's/couple's decision. At the same time, staff may struggle with the challenge of communicating a great deal of specialist knowledge. For example, if a woman/couple wish to eliminate a condition for future generations, they might prefer to accept an 'unaffected' embryo with a higher risk of misdiagnosis, rather than a 'carrier' embryo with a lower risk of misdiagnosis. This illustrates further how information may be negotiated according to a combination of the interests of the woman/couple contemplating the possibility of bringing up a child who might have 'problems'; the significance of degrees of certainty in the diagnosis; and the staff's professional goals and values. The scientist's description of framing the choice in this way appears to be an attempt to bridge these considerations within a professional commitment to the ethos of individual choice.

In this section it can be seen that staff held a range of views about women's/couples' decision-making concerning 'carrier' embryos, to some extent reflecting the different treatment goals of IVF and PGD. The framing of such information in ways that incorporate possible social implications of choices, together with support for women's/couples' autonomy, can be seen as attempting to create a bridge between professional knowledge, individual autonomy and wider social, ethical and professional values. We argue that these bridging attempts illustrate how relational autonomy might better fit the ethical framework of staff at this clinic.

Sex selection for social reasons

Although it is currently illegal in the UK to allow sex selection of embryos for social reasons, some staff anticipated difficulties in relation to the potential desire of some women/couples to 'add on' sex selection as another possibility when going through PGD. In this section, we present dilemmas that staff discussed in relation to the possibility of sex selection for social reasons, grouped into three themes. The first theme relates to weighing harms that might follow from the consequences of facilitating fully informed choice. The second theme concerns framing choices with the effect of prioritising the potential health and social interests of the child over women's/couples' preferences for a child of a particular sex. The third theme relates to the varying views of staff coming from different occupational or disciplinary backgrounds in their attitudes to supporting individual choice in this area.

Weighing of harms and information giving

Although staff were clear that women/couples would not currently be allowed to use PGD purely for sex selection on social grounds, many were unhappy that information about the sex of the embryo could potentially be used in the future by women/couples, to select embryos of a particular sex. Awareness of this possibility had led staff in a particular case in the past to consider withholding information about the sex of embryos, because they did not want to assist women/couples in choosing embryos using this criterion. For some staff,

however, withholding that information could be problematic. Members of EDG 1 referred to the ethos of giving full information to clients as a key value. Withholding information in this scenario thus failed to resolve their dilemmas completely, because withholding information was an uncomfortable stance to take professionally:

- Counsellor, 10: With this couple we were actually choosing to withhold information from them, and that was our choice as a team. And I think now we've felt less comfortable with that.
- Scientist, 19: Yes, it's all because you're withholding information. It is . . . about what your stand is and the fact that you have information and you've decided not to give that to them. You can be equally as uncomfortable with that as to . . . the other sort of consideration.

Further, decisions to withhold information, based on perceived good intentions, could lead to unintended consequences that might be worse than the harm being avoided. A member of EDG 4 raised this dilemma by referring to a case in which such information was withheld following prenatal diagnosis, making a comparison with withholding this information at the PGD embryo transfer stage. The scenario concerned a case from another clinic in which a couple were suspected of having prenatal diagnosis mainly in order to detect the sex of the fetus. The staff feared this information would lead to termination of a female fetus, so they decided not to report it to the couple:

- Scientist, 3: The fetus was actually male. The couple terminated the pregnancy anyway, because they didn't want to take the risk that it might be female . . . to me that was a very good lesson, in that sometimes you can try to intervene for the best of reasons, and actually it still goes horribly wrong.

The lesson being drawn here was that weighing the harms and deciding to withhold information led to unintended consequences that the staff were equally uncomfortable with: it all went '*horribly wrong*' and a male fetus (which the couple wanted) was aborted (which the staff wanted to avoid).

The discussions concerning these dilemmas illustrate the difficulties staff reported in weighing possible harms to women and female fetuses that they saw as flowing from giving women/couples information which might be used to facilitate social sex selection, whether that facilitation was intentional or not. These dilemmas included awareness of untoward and unintended consequences.

Dilemmas could also relate to potential harms to the staff themselves, in terms of their professional standards, personal consciences and the law; or conversely, saving their own consciences at the expense of women. The harm of denying their professional ethos to give full information was weighed by EDG 2 against the harm to their conscience when considering the consequences for the woman:

- Counsellor, 28: We're not contributing to the termination of a female fetus [by disclosing the sex of the fetus], so therefore, in one sense, we're kind of squeaky clean. . . . but as this poor woman comes back after her third late termination . . . probably done under not such ideal conditions . . . , you know, we feel less squeaky clean . . .
- Scientist, 8: But I don't see that giving her the same information that every other woman in the department gets is in some way dirtying your hands. I

mean she's going to find out later and she will have a later termination and so, in a way, it's saving your own conscience at her expense.

Even if social sex selection became legal, some staff would not be happy with the consequences of giving full information when women's/couples' expression of autonomy might result in practices of which staff did not approve. At the same time, some staff also found that deciding *not* to give information that might facilitate such choices could be problematic, because withholding information conflicted with the value of giving women/couples all the information generated as an obligation within the ethos of supporting fully-informed choice and individual expression of autonomy (Williams, Alderson and Farsides (2002b).

In the EDGs, staff engaged in articulating their own views about the acceptability of some choices, and in attempts to limit choices accordingly. It seemed that the model of individual autonomy that they ostensibly espoused did not turn out entirely to fit their negotiation and support of women's/couples' choices. Instead we consider that relational autonomy better describes the ways in which the staff's work is informed by an awareness of the wider social, legal, emotional and professional context and implications of their work and women's/couples' choices, rather than a narrower focus on the woman's/couple's immediate interests.

Choice, sex selection, and a successful pregnancy

Many staff were uncomfortable with allowing preferences for a child of a particular sex to take priority over the potential for particular embryos to implant successfully and ultimately to develop into a 'healthy baby'. The clinical scenario referred to is that *if* there are more than two embryos available for transfer in a cycle, a decision needs to be made about which embryos to select, taking into account a range of factors relating to the quality and genetic status of the embryo. Since the ethos is not to withhold information from women/couples, including information about the sex of the embryo, some staff were concerned that decisions could, in the future, be dominated by that factor, rather than the likelihood of a successful pregnancy. In this situation, staff would see their role as trying to frame the information so as to highlight their goal of achieving a successful pregnancy, yet maintaining an ethos of facilitating choice for the couple:

Scientist, 19: We would be going on the embryo quality at that stage. That gets the first ranking, and then the second ranking comes in on the genetics or status we've given, so in that way, hopefully there isn't a decision. If there is, if you do know quality-wise, it's that the two best ones go in.

Counsellor, 10: . . . ultimately you do put it to the couple that it is their decision. So they then are taking the decision, 'am I more likely to get pregnant on the cycle, or am I really, really wanting that male pregnancy, and less worried about actually achieving a pregnancy?' And I think if you put it to the couple like that, ultimately they're their embryos and it's their decision (EDG 1).

In these comments the first priority for the scientist is the quality of the embryo, then the genetic status, so that 'hopefully there isn't a decision' about the sex of the embryo. The 'hopefully' may refer to not wishing to facilitate sex selection for social reasons, or a wish to avoid an ethically contentious issue. The counsellor espouses the conventional ethos of supporting the couple's own decision, yet this is a delicate balance to achieve in practice.

A bridge is attempted by acknowledging that for some couples a male pregnancy is an extremely desired goal – it is what the couple ‘really really’ want. On the other hand, the counsellor puts the choice in terms of women/couples choosing the male embryo, but possibly failing to get pregnant. If the staff ‘put it to the couple like that’, they can fulfil their professional commitment to supporting women’s/couples’ choice, whilst framing the question in a way that could suggest it would be illogical to pursue the aim of having a male child to the point of not getting pregnant at all.

In this way we can see that although the staff use the language of patient choice, there may be a subtle framing of information in particular ways. This framing can be seen as an attempt to create a bridge between supporting women/couples to make choices but at the same time hoping that their choices will not conflict with professional values. These include the view that successful pregnancy and the birth of a healthy child should take priority over social sex selection. We suggest that these ‘bridging’ attempts illustrate how the inclusion of professional values represents an extension to the conventional model of individual autonomy, and that this is captured by the concept of relational autonomy.

The influence of different occupational/disciplinary backgrounds

In the following exchange, differences between procedures followed by those working primarily in IVF and those followed in PGD, indicate how occupational differences in experience and practice can overlap with personal views, so that the overall team contains a range of opinions and moral views:

- Embryologist, 33: . . . Without knowing the sex, [in IVF] we look at a cohort of embryos, and we go: ‘This is the best one’. We have that information when we know the sex of the embryo . . . but we still look at the embryos and go: ‘This is the best one, it’s the one we should be putting back’, regardless of what sex it is . . .
- Scientist, 2: But what will happen with PGD is you’ll have three embryos, that is, when we’re lucky if we get three nice embryos. And [in terms of quality] . . . they’re much of a muchness and one is a boy and two girls, or two boys and one a girl. And then you’ll be saying, ‘Right, okay, they’ll [couple] make the final decision which ones we pick based on sex’, because they’ll know from the test which one’s which. And because they’re much of a muchness, they may even go for a bit better one or a bit less one just because of the sex of the embryos, because at the end of the day, that’s what they’d like.
- Embryologist, 33: But there’s still a distinction. You still have that mild distinction from an embryological point of view as to which ones would look the best for development.
- EDG facilitator: And would you always want that to be the trump card?
- Embryologist, 33: Yes (EDG 5).

Here, it becomes clear that the scientist and embryologist agree they would both like the couple to choose according to the quality of the embryo, but the scientist’s experience of people making choices in PGD is that sometimes it seems that women/couples would like to include in their decision the sex of the child they would prefer. Thus PGD poses new dilemmas for staff in potentially facilitating choices that are not offered in IVF. In a sense PGD is a hybrid of fertility and genetics technologies, so staff from those and other disciplines have to learn not only about each other’s clinical practices, but also, their ethical

approaches. During the EDGs, such a learning process was sometimes visible with professionals discovering some differences as well as similarities.

This section has explored how staff talked about potential dilemmas relating to facilitating and framing social sex selection in the PGD clinic. These dilemmas include reconciling their belief in individual autonomy as a key value with the reality that women/couples can potentially exercise that autonomy in ways they might find objectionable, and the knowledge that limiting information can lead to unintended consequences. In some cases staff may frame the information given to women/couples in particular ways to bridge the gap between somewhat conflicting values. Therefore, the technological assistance they offer women/couples, together with their own professional and personal values, all play a part in shaping the conditions and context of decision-making. We suggest that the concept of relational autonomy, as opposed to individual autonomy, better describes the principles and practices underlying the ways that staff frame choice for women/couples, because it acknowledges that the women's/couples' choices are influenced by, and have an impact upon, the staff's personal, professional and moral interests, values and practices (Mackenzie and Stoljar 2000). Our data also support Donchin's (2000) use of relational autonomy as a concept that captures how the 'self-determining self' continually remakes itself in response to changing relationships with others, including the ways in which institutions configure and limit options. Finally, differences between the goals, values and experiences of different occupational groups may also play a part in how choices are configured, and contribute to our understanding of some of the dilemmas posed by the multidisciplinary nature of PGD.

Discussion and conclusions

Individual patient choice has been a dominant rhetoric in UK health policy over the past two decades, but how far can the notion be stretched when it involves such complex information, decisions, and potential influences from and on society? In what ways do healthcare staff mediate the effects of broader social relations and influences on women/couples and their choices, and the effects of those choices on society? The proliferation of studies on individual women's/couples' choices in relation to genetic and reproductive technologies contrasts with the comparative lack of attention to the people who implement these technologies (Kerr 2004). This paper helps fill this gap by reporting on a series of multidisciplinary EDGs held for staff to explore some of these wider questions.

The staff who participated in the EDGs espoused the consensus that PGD as a technique is justified to help women/couples known to be at high risk of having a child with a serious genetic condition to select an 'unaffected' embryo in the hopes of having a 'healthy child'. However, they did not hold completely homogenous views when more complex versions of this narrative emerged in the groups and for some of the participants, the complexities took them into unwelcome areas. Even though in each of the scenarios discussed, the testing being done is to detect markers for specific genetic conditions, the nature of the tests potentially allows for more problematic additional choices to be made. While the simpler purpose or narrative of 'selecting unaffected embryos' would pose fewer ethical dilemmas for most staff, the more complex choices that the tests entail bring the staff into territory that is not so closely defined by the principle of seeking to reduce or prevent harm. For example, allowing women/couples to reject carrier embryos is seen by some staff as a less acceptable form of eugenics, ensuring the eradication of the genetic 'problem' for future generations beyond the future of the child being created; while others accept this as a

means of preventing suffering. The future possibility of facilitating sex selection for social reasons is seen by some staff as unacceptable assistance to enable women/couples to act on social wishes rather than preventing a medically defined harm; whilst others do not object to it so strongly. The EDGs allowed us to map these ethical 'grey areas' for staff in this UK setting, and to see how these had arisen in the context of particular developments in technology, and differences in the experience and practices of particular occupational groups (Farsides *et al.* 2005).

Consensus was also expressed that a key value of their service is to assist women/couples making informed choices during their treatment. However, while ostensibly promoting individual choice within a guiding ethical framework of 'secular-liberal autonomy', it seemed that staff support for individual autonomy had its limits. Our study complements the findings of Scully *et al.* (2006) because, like the lay participants in that study, staff expressed doubts that choice was always positive. They were sensitive to the wider implications of individual choices, and were not sure that expressing preferences for a child of a particular sex was a commendable attribute of potential parents. Discussion of practice implicitly confronted staff with the question of whether patient choice is a desirable policy to espouse *per se*, or whether it should be offered within a limited range of options and outcomes (Williams, Alderson and Farsides, 2002c). The clinic's ethos is to support women/couples by providing full information with which to make choices. Many of them, however, felt uncomfortable with the possibility of facilitating women's/couples' particular choices in practice. As Pilnick (2002) comments in relation to withholding information about the sex of the fetus:

'it is highly problematic to offer screening and testing and to ask people to make an informed choice on the basis of these test results, if we then tell them that their choice is unacceptable' (2002: 76–77).

Our findings support and extend Pilnick's view, because we argue that in many ways, withholding information can be as problematic for staff as it is for women/couples (Williams *et al.* 2002b). If sex selection is allowed in the UK in the future, it could be that their commitment to give full information might change. Staff in our study had developed an acute awareness of these complexities, and experienced uncertainty and ambivalence themselves about the wider social context and effects of their work on women's/couples' choices, and the implications of their involvement in facilitating these choices. They were sometimes caught between that awareness and their professional and personal imperatives to shape the process.

This paper has mapped some of the choices women/couples make, and could potentially make in relation to PGD, and some possible unintended consequences that might follow from staff attempting to shape choices. Ettore (1999) suggests that too much information can ultimately make people more dependent on medical professionals, and many other studies in reproductive medicine have shown that staff acknowledge how, if information is put in a particular way, women/couples will often 'go along' with what is, in effect, being recommended (*e.g.* Press and Browner 1997, Rothman 1986). In this sense we can see that PGD staff shape the information, and not solely in the technical sphere of information. As Williams *et al.* (2002a) found in relation to pre-natal screening, the boundary between choice and coercion is not a clearcut one for health practitioners, with slippage occurring between these concepts. The opportunities for slippage in giving the diagnostic information following PGD include those afforded by the use of languages of risk, probability, and social implications that may be inferred in such classifications as 'carrier', 'affected', 'unaffected',

'normal' and 'best/good' embryos. These categories can also reflect differences in professional experience and practice.

It has been argued that diagnostic information to inform choice may be conveyed in a language of risk and probability (Rapp 1999, Webster 2002) yet still contain personal, social and professional values, and our findings support this. However, rather than suggesting our data support critiques of social control in reproductive and genetic healthcare, we consider that staff appeared to be operating according to principles that would better fit within a model of relational autonomy. When staff discussed the more difficult 'grey areas' that tested their resolve to support women's/couples' individual choice and autonomy, they frequently argued it was not sufficient simply to allow women/couples to express their own reproductive autonomy, given their fears of the possible collective social effects of, for example, rejection of carrier embryos and sex selection for social reasons. We found evidence supporting Kerr's (2004) questioning of the tendency for individual choice and autonomy to be used as a fall-back position to unite otherwise quite disparate interests and discourses. She believes the ideal of free, individual choice to be a chimera, as choices are necessarily made within social contexts which produce unintended consequences and sometimes 'impossible choices' (2004: 72). We found that the fall-back position did not always stand up in our discussions with staff. However, rather than seeing this as indicating a lack of commitment to women's/couples' individual choice and autonomy, we suggest that this occurs when staff attempt to achieve simultaneous facilitation and framing of choices for women/couples. Efforts to achieve a more nuanced engagement through supporting and shaping the capacity for autonomy and choice (Dodds 2000), whilst simultaneously acknowledging the inherently complex social and ethical implications of their work, indicate that relational autonomy may be a more suitable ethical model to describe the work undertaken in this often controversial clinical context.

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References

- Alderson, P., Farsides, B. and Williams, C. (2002) Examining ethics in practice: health service professionals' evaluations of in-hospital ethics seminars, *Nursing Ethics*, 9, 508–21.
- Allen, D. (1997) The nursing-medical boundary: a negotiated order? *Sociology of Health and Illness*, 19, 4, 498–520.
- Braude, P., Pickering, S., Flinter, F. and Ogilvie, C. (2002) Preimplantation genetic diagnosis, *Nature Review Genetics*, 3, 941–53.
- Brock, D.W. (2005) Shaping future children: parental rights and societal interests, *The Journal of Political Philosophy*, 13, 377–98.
- Buchanan, A., Brock, D.W., Daniels, N. and Wikler, D. (2000) *From Chance to Choice: Genetics and Justice*. Cambridge: Cambridge University Press.

- Casper, M.J. (1998) Negotiations, work objects, and the unborn patient: the interactional scaffolding of fetal surgery, *Symbolic Interaction*, 21, 4, 379–400.
- Dodds, S. (2000) Choice and control in feminist bioethics. In Mackenzie, C. and Stoljar, N. (eds) *Relational Autonomy: Feminist Perspectives on Autonomy, Agency and the Social Self*. New York: Oxford University Press.
- Donchin, A. (2000) Autonomy and interdependence: quandaries in genetic decision making. In Mackenzie, C. and Stoljar, N. (eds) *Relational Autonomy: Feminist Perspectives on Autonomy, Agency and the Social Self*. New York: Oxford University Press.
- Ehrich, K., Williams, C., Scott, R., Sandall, J. and Farsides, B. (2006) Social welfare, genetic welfare? Boundary work in the IVF/PGD clinic, *Social Science and Medicine*, 63, 1213–24.
- Ettore, E. (1999) Experts as ‘storytellers’ in reproductive genetics: exploring key issues, *Sociology of Health and Illness*, 21, 5, 539–59.
- Farsides, B., Williams, C. and Alderson, P. (2005) Aiming towards ‘moral equilibrium’: health care professionals’ views on working within the morally contested field of antenatal screening, *Journal of Medical Ethics*, 30, 505–09.
- Getz, L. and Kirkengen, A. (2003) Ultrasound screening in pregnancy: advancing technology, soft markers for fetal chromosomal aberrations, and unacknowledged ethical dilemmas, *Social Science and Medicine*, 56, 2045–57.
- Haimes, E. (2002) What can the social sciences contribute to the study of ethics? Theoretical, empirical and substantive considerations, *Bioethics*, 16, 90–113.
- Hedgecoe, A. (2004) Critical bioethics: beyond the social science critique of applied ethics, *Bioethics*, 18, 120–43.
- Human Fertilisation and Embryology Authority (2005) *Guide to Infertility and Directory of Clinics 2005/06*. London: HFEA/Dr Foster.
- Kerr, A. (2004) *Genetics and Society: a Sociology of Disease*. London: Routledge.
- Lavery, S., Aurell, R., Turner, C., Castello, C., Veiga, A., Barri, P. and Winston, R. (2002) Preimplantation genetic diagnosis: patients’ experiences and attitudes, *Human Reproduction*, 17, 9, 2464–67.
- Mackenzie, C. and Stoljar, N. (2000) Introduction: Autonomy Reconfigured. In Mackenzie, C. and Stoljar, N. (eds) *Relational Autonomy: Feminist Perspectives on Autonomy, Agency and the Social Self*. New York: Oxford University Press.
- Petersen, A. (2006) The best experts: the narratives of those who have a genetic condition, *Social Science and Medicine*, 63, 1, 32–42.
- Pilnick, A. (2002) *Genetics and Society*. Buckingham: Open University Press.
- Press, N. and Browner, C. (1997) Why women say yes to prenatal diagnosis, *Social Science and Medicine*, 45, 979–89.
- Rapp, R. (1999) *Testing Women, Testing the Fetus*. New York: Routledge.
- Ritchie, J. and Spencer, L. (1994) Qualitative data analysis for applied policy research. In Bryman, A. and Burgess, R.G. (eds) *Analysing Qualitative Data*. London: Routledge.
- Rothman, B. (1986) *The Tentative Pregnancy*. New York: Viking Press.
- Scully, J.L., Banks, S. and Shakespeare, T. (2006) Chance, choice and control: lay debate on prenatal social sex selection, *Social Science and Medicine*, 63, 1, 21–31.
- Shakespeare, T. (1998) Choice and rights: eugenics, genetics and disability equality, *Disability and Society*, 13, 5, 655–81.
- Shakespeare, T. (1999) ‘Losing the plot’? Medical and activist discourses of contemporary genetics and disability, *Sociology of Health and Illness*, 21, 5, 669–88.
- Sherwin, S. (1998) A relational approach to autonomy in health care. In The Feminist Health Care Ethics Research Network, Susan Sherwin Coordinator. *The Politics of Women’s Health: Exploring Agency and Autonomy*. Philadelphia: Temple University Press.
- Soini, S., Ibarreta, D., Anastasiadou, V., Aymé, S., Braga, S., Cornel, M., Coviello, D.A., Evers-Kiebooms, G., Geraedts, J., Gianaroli, L., Harper, J., Kosztolanyi, G., Lundin, K., Rodrigues-Cerezo, E., Sermon, K., Sequeiros, J., Tranebjaerg, L. and Kääriäinen, H. (2006) The interface between medically assisted reproduction and genetics: technical, social, ethical and legal issues.

- PGD and Europe. European Society of Human Reproduction and Embryology Monographs* Volume 1, October, accessed at <http://eshremonographs.oxfordjournals.org/>
- Wainwright, S., Williams, C., Michael, M., Farsides, B. and Cribb, A. (2006) Ethical boundary work in the stem cell laboratory, *Sociology of Health and Illness*, 28, 6, 732–48.
- Webster, A. (2002) Innovative health technologies and the social: redefining health, medicine and the body, *Current Sociology*, 50, 443–57.
- Williams, C. (2006) Dilemmas in fetal medicine: premature application of a technology or responding to women's choice? *Sociology of Health and Illness*, 28, 1, 1–20.
- Williams, C., Alderson, P. and Farsides, B. (2002a) Is nondirectiveness possible within the context of antenatal screening and testing? *Social Science and Medicine*, 54, 339–47.
- Williams, C., Alderson, P. and Farsides, B. (2002b) Dilemmas encountered by health practitioners offering nuchal translucency screening, *Prenatal Diagnosis*, 22, 216–20.
- Williams, C., Alderson, P. and Farsides, B. (2002c) 'Drawing the line' in prenatal screening and testing: health practitioners' discussions, *Health, Risk and Society*, 4, 61–75.