

Experiencing new forms of genetic choice: Findings from an ethnographic study of preimplantation genetic diagnosis

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Abstract

Contemporary scientific and clinical knowledges and practices continue to make available new forms of genetic information, and to create new forms of reproductive choice. For example, couples at high risk of passing on a serious genetic condition to their offspring in Britain today have the opportunity to use Preimplantation Genetic Diagnosis (PGD) to select embryos that are unaffected by serious genetic disease. This information assists these couples in making reproductive choices. This article presents an analysis of patients' experiences of making the decision to undertake PGD treatment and of making reproductive choices based on genetic information. We present qualitative interview data from an ethnographic study of PGD based in two British clinics which indicate how these new forms of genetic choice are experienced by patients. Our data suggest that PGD patients make decisions about treatment in a complex way, taking multiple variables into account, and maintaining ongoing assessments of the multiple costs of engaging with PGD. Patients are aware of broader implications of their decisions, at personal, familial, and societal levels, as well as clinical ones. Based on these findings we argue that the ethical and social aspects of PGD are often as innovative as the scientific and medical aspects of this technique, and that in this sense, science cannot be described as "racing ahead" of society.

① Keywords: ???

Introduction

In Britain today, couples who know that they run a risk of passing on a serious genetic condition to their offspring are in a difficult position when it comes to making decisions about reproduction. For many of these conditions, contemporary genetic science does not offer the hope of treatment or cure for potential children. Instead, what is offered is the chance to diagnose fetuses in-utero or embryos in-vitro. Clinical genetics can provide parents with an understanding of what is likely to happen to their future child, but cannot alleviate this outcome for any individual.

Based on such a diagnosis, couples can engage with clinical reproductive services to make choices about which fetuses or embryos they hope to eventually give birth to. Termination of pregnancy is one option available to those who receive a prenatal foetal diagnosis. A more complex technique, preimplantation genetic diagnosis (PGD), offers couples the chance to make a choice of embryos at

the eight cell stage before they are transferred to the woman's uterus. This technique, whilst significantly reducing the potential need for termination, involves the couple in an in-vitro fertilization (IVF) cycle, with all the attendant difficulties of such treatment.

In the mass media, PGD is often referred to as "the designer baby technique", a figuration that represents the choices involved in PGD as trivial and fashion-driven, or as relating, for example, to choice of hair or eye colour. Social scientific research challenges this representation and provides a more nuanced characterization of the new forms of choice involved in PGD. It investigates the meanings of these choices for couples undergoing them and their implications on a broader social scale.

An ethnographic study of PGD

Background

This paper reports on a subset of findings from an 18-month ethnography of preimplantation genetic

diagnosis (PGD) in Britain. This study was funded under the Economic and Social Research Council and the Medical Research Council's jointly sponsored "Innovative Health Technologies" programme. The study was based in two PGD clinics: one at Guy's and St Thomas's hospitals in London, and the other at Leeds General Infirmary in the northeast of England.¹

The term "ethnography" comes from anthropology, and refers to a method of research based on participant-observation in the field. More recently, the term has taken on a broader set of meanings, describing an approach that is based on immersion in the field of study, in both practical and intellectual ways (Marcus, 1995). In this study we used a number of ethnographic methods.

First, we undertook participant-observation in the PGD clinics and laboratories, in scientific and policy-related meetings, and in relevant parliamentary sessions. These observations allowed us to collect a range of different understandings, or "versions", of what is seen to be at stake in a wide range of social and technical encounters focussed around PGD. Second, we conducted twenty-two formal interviews with a range of people involved in PGD: couples undergoing the technique, clinicians, nurses, genetic counsellors, scientists, policymakers and lobbyists. Here we focussed on diverse individuals' connections to PGD, and their understandings of its social and ethical implications. We also conducted supplementary informal interviews, for example with PGD coordinators and embryologists, to clarify events observed and to discuss issues arising from these events. Third, we analysed written documents concerning PGD, including reports from policy bodies and lobby groups, medical and scientific papers, patient information leaflets, medical literature, and media reports.

Each of these methods produces different forms of data, namely field notes, interview transcripts, and textual analyses. In bringing these diverse data together we attempt to provide a complex social "portrait" of PGD in Britain during a period of its expansion and increasing visibility (Franklin & Roberts, 2002, forthcoming). This form of qualitative social science does not provide direct or simple ("yes" or "no") answers to social and ethical questions about the new genetics or new reproductive technologies. Rather, it explores the complexities of questions provoked by these new forms of knowledge and practice, and leads to the positing of further critical questions.

Method

As part of our ethnography, we investigated what the offer of the choices constituted by PGD looks like from the point of view of people encountering this

technique—both for the first time (synchronously), and over time (diachronically). How do they experience and describe this choice? How does it fit into their lives, and their reproductive histories and futures? We addressed these questions through semi-structured personal interviews with 21 patients undergoing PGD treatment at the Guy's and St Thomas's clinic. Interview data is analysed in the light of observations undertaken at this clinic from February 2001–August 2003.

The interviewees ranged in age from late twenties to early forties, and all but two of them were white British. Although all of the interviewees owned their own homes and were almost all in skilled employment, there were significant income differences amongst them, with some stating that they had no difficulties in paying for PGD treatment, and others saying that the treatment was a considerable financial burden. Interviews were conducted by one or both researchers, in the participants' homes, and in all but two cases with both the male and female partners simultaneously. Interviews lasted from one to three hours and were tape recorded and transcribed verbatim.² All individuals have been given pseudonyms, and strict measures to protect confidentiality have also required any other possibly identifying details to be removed or altered. The interviews were open-ended and began by asking participants to explain how they had initially arrived at PGD. Answers to this question were often lengthy and involved participants telling detailed stories of significant loss and distress in their reproductive histories. These stories led into discussions about their experiences of treatment, and then into broader issues relating to their own and other's perceptions of PGD, and to genetic information and reproductive choice. The interviews were challenging and emotional experiences for all participants, and couples often commented that it was helpful to reflect on their treatment, and to talk through aspects of their experience of PGD, with informed but non-medical interlocutors.

Observations were conducted during PGD clinics and at random times throughout the year. Both observational field notes and interview transcripts were analysed for recurring themes and issues, and our arguments are based on this analysis. Several of these arguments have been presented orally in multiple forums, including academic and professional conferences nationally and internationally, public policy meetings, and in clinical team meetings. This article benefits from feedback received on these occasions.

PGD as a new form of choice

Across diverse social arenas, PGD is understood as providing a new form of reproductive choice for

some couples. This choice is based on the provision of previously unobtainable genetic information about eight cell embryos.

In Britain, PGD is regulated by the Human Fertilization and Embryology Authority (HFEA), a statutory body established in 1990 by the Human Fertilization and Embryology Act to regulate the new reproductive technologies being developed at that time. In 1999 the Labour government also established the Human Genetics Commission (HGC), replacing the Advisory Committee on Genetic Testing (ACGT), to provide independent policy advice on genetic matters. In 1999, a joint working party of the HFEA and ACGT conducted a public consultation on PGD (HFEA/ACGT, 1999), and from 1999–2001, a joint working group of the HFEA and the HGC met to discuss responses to this document. The consultation took place ten years after PGD was developed in Britain (Handyside, Kontogianni, Hardy, & Winston, 1990), at a time of increasing public concern regarding the new genetics and reproductive technologies more broadly, including the issue of “reproductive cloning”. The consultation was very specifically focussed, asking interested members of the public to give their views regarding the regulation of PGD by the HFEA. One hundred and twenty-four individuals and forty-seven groups responded to this consultation, the results of which are documented in a report, published November 2002 (HFEA/HGC, 2002).

In the HFEA/HGC report, PGD is defined as

[A] technique that combines genetic testing and IVF in order to offer those who are at significant risk of passing on a serious genetic condition the choice of selecting embryos that are unaffected before a pregnancy is begun (HFEA/HGC, 2002: i).

In this definition, increased reproductive choice is placed at the heart of PGD, namely “the choice of selecting embryos”. However, these choices are also seen to pose new challenges, and the HFEA/HGC report also acknowledges that clinicians, scientists, and indeed regulators, can be involved in difficult decision-making in relation to PGD. One recommendation states, for example, that

In the case of ethically difficult decisions [PGD treatment] centres may seek advice from a treatment ethics committee and this may be taken into account by a licence committee when considering an application [for a licence to conduct PGD in a specific case] (HFEA/HGC, 2002: 2).

Clinicians and scientists also describe PGD as a new form of choice. In a review article published in *Nature Genetics* (2002), for example, Braude, Pick-

ering, Flintner and Ogilvie (2002) describe PGD as providing “an alternative way forward” for a variety of couples. “PGD was originally developed as an alternative to prenatal diagnosis to reduce transmission of severe genetic disease for fertile couples with a reproductive risk,” they write, stating that, “Before the development of PGD, limited options were available to couples with a reproductive risk” (Braude et al., 2002: 941–2). In this context, Braude et al. suggest that “Preimplantation diagnosis provides an alternative way forward, not only for couples who have such reproductive risks, but also for couples who are unable to establish a viable pregnancy because of miscarriage caused by chromosome rearrangements” (Braude et al., 2002: 942). According to this clinical-scientific definition, PGD provides a very specific set of “alternative” choices for at least two categories of patients: those with reproductive risk related to a severe genetic disease, and those who are unable to sustain a pregnancy due to a chromosomal translocation.

Precisely which couples should be offered the choice of PGD is a technical, ethical and political question. The HFEA/HGC report recommends that specific guidelines be developed in relation to decisions around which “serious genetic conditions” PGD should be offered for (HFEA/HGC, 2002: 5). There is resistance in their report to the creation of a list of conditions meeting the criterion of seriousness, but there is a recommendation that PGD-specific guidance should be developed in order to facilitate decisions about appropriate access to PGD services. The report recommends that “PGD guidance should support difficult parental choices rather than appearing to discriminate against individuals with certain conditions” (HFEA/HGC, 2002: 5). There is a strong emphasis here on the role of patients in making these decisions, but also an explicit statement that “this treatment should not be available on demand” (HFEA/HGC, 2002: 5). Tension between patients’ desire for PGD and the need to set limits on its availability, then, is also central to discussions of PGD.

Couples choosing PGD

As noted previously, patients often come to PGD with complex medical and reproductive histories. In many cases, they have discovered that they carry a genetic condition either through a series of miscarriages, or the birth of a child with a severe or fatal disorder, such as cystic fibrosis or spinal muscular atrophy. One third of the patients we interviewed had had a child with a fatal condition, and in one case two children. An equal number had histories of multiple miscarriages due to genetic abnormalities. Those remaining had obtained their genetic diag-

noses after extended periods of infertility. Two of these infertile couples experienced miscarriage or termination (because of another medical or chromosomal condition) during PGD treatment. Only one couple we interviewed, then, had not lost at least one (and in many cases more than one) foetus or child due to genetic problems.

Couples experiencing multiple miscarriages or genetically-caused infertility had often spent many years trying to establish the cause of their difficulties. Almost all of them had engaged with multiple forms of reproductive assistance or related medical treatments, including IVF cycles, gamete donation, termination of genetically affected embryos, and post-miscarriage medical treatment. The attempt to obtain a diagnosis of their genetic problem had taken some couples a lot of time and effort, and a number of them reported both poorly managed and ultimately redundant treatment at other IVF clinics, in which the genetic aspects of their reproductive problems had remained unrecognized.

Arriving at the PGD clinic, then, was often described as an enormous relief. All of the patients we interviewed (who were, importantly, a self-selected sample who both decided in favour of undergoing PGD and were willing to participate in the study) reported that they had *already decided* that they wanted to attempt PGD before their arrival for their initial consultation session.³ These patients had all either experienced the birth of an affected child, or felt that they were unlikely to produce a foetus that would be carried to term. Their desire to undergo PGD, in other words, was motivated by their distress in the wake of multiple failed attempts at “normal” pregnancy, and/or IVF, and their desire not to repeat these experiences. For such patients, then, deciding to undertake PGD becomes “a choice out of necessity” or not really a “choice” in the normal sense at all. Like Belinda in the quote below, many patients were keen to distinguish this sense of choice as *an expression of parental obligation* from the trivial “consumer”, or narcissistic, choices implied in mass media descriptions of PGD as the “designer baby” technique.

Belinda: It’s how you approach the word “choice” isn’t it? This gives us the choice of healthy from unhealthy, as opposed to choosing, you know, a blonde or a brunette, or a boy or a girl. This is choice out of necessity. Not for any other reason.

Interviewer: So you haven’t found –

Belinda: [interrupts] So, I don’t think we have a choice really.

Particularly for parents who have watched their children suffer and die as a result of genetic disease, the desire to undertake PGD is not about having a

“designer” or even necessarily a “normal” baby, but a child who lives with a tolerable quality and length of life. Anne and Daniel lost their first child to spinal muscular atrophy (SMA) at 11 months of age and discussed their reasons for using PGD with us in the light of this experience, emphasising the *certainty of fatality* associated with SMA.

Anne: I mean if we was to find out that we was carriers of something else, and we were just going to produce a child that would inevitably be disabled, or whatever, we wouldn’t use PGD. You know, we see it as something that can . . . prevent children dying, basically, that’s why we’re using PGD.

Daniel: And it’s not even a case of um, I think with SMAs, it’s not even a case of “Well they might die”. They will! There’s no question about it, they will!

Although others were less sanguine about the possibility of disability, all the participants we interviewed had thought seriously about the impact having a disabled child would have on their own and their extended families’ lives. Their thoughts about the prospect of disability and their carefully considered decisions to undertake PGD indicate that these couples are neither passive consumers of PGD services due to their increasing availability, nor that they are compelled to undertake it due to the technological “imperative” it creates. This finding strongly correlates with those of other social scientists researching the new genetics, who have shown that patients, and the wider public, have sophisticated, nuanced, and multi-faceted understandings genetic choice in the context of reproductive medicine (Edwards, 2000; Edwards Franklin, Price, Hirsch, & Strathern, 1999; Rapp, 1999; Thompson, 2001). Consumers of genetic medicine (and of medicine in general) are also becoming more and more active in their approach to information gathering and decision-making (Novas and Rose, 2000; Rapp, Heath, & Taussig, 2001; Rabinow, 1992). Coming to PGD requires effort, time and money: all the PGD patients we interviewed had spent significant periods on the internet, reading books, media and watching documentaries, gathering information about the technique. They had also spent a lot of time talking with partners, friends, families and genetic disease support groups. Our study suggests couples do not enter into or continue PGD treatment in a casual or “knee jerk” fashion, but on the basis of careful thought. As one female interviewee remarked, “This isn’t about designer stuff at all! This is serious stuff”.

The extent of concern about the implications of PGD we encountered in our interview set also demonstrated widespread and highly reflexive concern with ethical questions associated with the

choices offered by PGD. This finding is consistent with one of the main emerging conclusions of social scientific and ethnographic research on genetic information and reproductive decision-making—that treatment decisions are always made with reference to a range of over-lapping contexts, including personal, familial, and wider social contexts (see, for example, Rapp, 1999; Finkler, 2000; Rapp, et al., ③ 2001; Thompson, 2001). Sally, a young woman who was in the middle of PGD treatment when we interviewed her, demonstrated a keen awareness of the ways in which her and her husband’s reproductive choices took place within a wider frame:

Sally: We are very, very open—really open about it, and it’s just every decision we take is obviously primarily for ourselves, but it affects everyone else as well, all our friends, our families. Every decision we make is indirectly going to affect somebody else, and I think that’s where a lot of people don’t seem to get [PGD and] . . . IVF.

This sense of responsibility creates a serious, but not necessarily unwelcome, burden. As Sally remarks, “It’s just that we think for everyone else as well”. In her 15-year study of women’s decision-making in the context of amniocentesis, American anthropologist Rayna Rapp argues that women making reproductive decisions based on genetic information should be called “our contemporary moral pioneers” (Rapp, 1999: 317). “At once held accountable at the individual level for a cascade of broadly social factors which shape the health outcome of each pregnancy, and individually empowered to decided whether and where there are limits on voluntary parenthood”, Rapp writes, “women offered an amniocentesis are also philosophers and gatekeepers of the limits of who may join our current communities” (Rapp, 1999: 317–8). Sally’s experience of “thinking for everyone else” resonates strongly with this description and stands in contrast to the view of PGD patients as “choosy” parents acting out of self-interest, ambition, or even whimsy.

This sense of the complexity of decision-making and of coming to realise that these are social and not merely personal decisions, often came to the fore when discussing the role of the media in creating public awareness of PGD and new forms of genetic information. When asked to respond to the media tag “designer babies”, for example, our interviewees quickly distinguished their own desires for PGD and those presumed under this rubric. Despite making strong distinctions between choosing sex and trivial physical characteristics and selecting embryos that would not develop genetic disease, however, couples were aware of “grey areas”. Alongside feeling intensely irritated by media coverage of PGD, for

example, Anne understands the complexities of “drawing the line” between appropriate and inappropriate uses of the technique.

Anne: I find myself shouting at the TV, you know, saying, “That’s not what it’s about!” There’s nothing “designer” about having child that lives longer than 11 months . . .” . . . But I can understand it is a very grey area. Because obviously . . . we’ve used PGD because we didn’t want to have another child that was going to die within 12 months. But, I mean, . . . at what point do you draw the line? At a child that dies at 2 years, 5 years, 10 years, 20 years, 30 years? Where? . . . What conditions are we going to allow PGD to be used for? . . . I don’t know where the line should be drawn.

In these discussions, couples often argued that it is important that such vital decisions not be left up to individuals, and emphasised the need for regulation. They felt that allowing individuals to make decisions outside of regulatory frameworks could lead to the use of PGD for the “wrong” reasons, such as sex selection, which could jeopardise the technique for others like themselves.

Steven: I think it’s one of those things that’s got to be taken out of the individual’s decision-making process. I don’t think an individual should be allowed to make that decision about the baby . . . It’s got to be a higher level because if—you know, like we’ve got a problem, that’s why we’re going through it. Unless there’s a problem, a genetic problem, then—that’s the only reason you should go through it! It should have nothing to do with, you know, whether folks are interested in how intelligent, or prefer a baby boy.

This need for limits is a common theme of discourses around the new genetics and reproductive technologies. A multi-sited ethnographic study conducted in 1990–1 by a team of social anthropologists in Britain (Edwards, et al., 1993, 1999) for example, concluded that “Concern about the appropriate limits to human intervention . . . was a feature common across all of the [study’s contexts], lay and professional” and suggested of these limits that “their cultural dimension is not to be underestimated” (Strathern, 1991: 8–9). Similarly, the HFEA/HGC’s public consultation on PGD found that a common concern expressed by respondents was the need for strict limits to the use of PGD so that it could only be used for “a limited number of specific and serious conditions” (HFEA and HGC, 2002: i). In the case of PGD, this need for limits must be balanced against the strongly felt obligations to prevent suffering in future children. This need for balance is evident in the deliberations engaged in by patients, clinicians, scientists and policy makers, and indicates that decisions concerning PGD cannot be made according to simple classifications of “right” or “wrong”.

The wider contexts of choice

As in Franklin's previous study of IVF (1997), we found a consistently high level of awareness among PGD patients of the procedure's considerable limitations and the significant likelihood of its failure. Indeed, the most consistently positive response to the Guy's and St Thomas's clinical staff repeated by all patients we interviewed was how much they appreciated the ways in which the PGD team did not exaggerate the possibilities of success. In observing clinical consultations at both clinics participating in the study, we noted that staff went to considerable lengths to explain the possible causes of treatment failure, using diagrams to demonstrate the various points in a cycle at which failure could occur.

Being informed about the difficulties of treatment and the potential for failure did not change the decision of the patients we interviewed to proceed with treatment. Rather, and somewhat unexpectedly, we found that the explicit, and at times even insistent, communication of uncertainty provided at the clinic created an increased sense of trust and respect, and a greater sense of trust in clinical and scientific authority. This is described separately by both Karen and by Joanna in their positive accounts of their initial consultation sessions with PGD staff.

Karen: I think the *first* time we went, the initial consultation we had [was] with the clinical co-ordinator at St Thomas's . . . Um, and she was very sort of—I think she wanted to paint like the blackest picture really. And we came away thinking, “Crikey, that doesn't sound very good!” [laugh] But we were still determined to . . . , I think, to do it, weren't we?

Joanna: And they just, they talked through everything and showed us—I thought they were, they were *brilliant*. They were very clear. They explained everything really *clearly* and really like, not *patronisingly* but very simply, so you didn't feel silly about asking questions about things. They showed us lots of pictures as well so it was like very easy to understand exactly what was happening. Um, they talked to us about how we felt about it, and sort of, I think, made sure that we understood exactly what was going on and . . . also made it very clear that it wasn't you know, that the, the actual chances of it working . . . are—it's not a certainty. You don't say “Oh I'm having PGD so therefore I'm going to walk away with a baby”.

This sense of being told from the earliest days of the uncertainties of treatment, that “You don't say ‘Oh I'm having PGD so therefore I'm going to walk away with a baby’”, helps patients to form a more realistic picture of possible sources of failure, and to expand their thinking to encompass other options if PGD is not eventually successful. With a clear understanding of the technical difficulties associated with PGD, and

often after having had at least one failed cycle, the patients we interviewed had all put serious thought into alternative options. These included getting pregnant “naturally” and using prenatal diagnosis, gamete donation (from siblings or strangers), adoption (international or local), surrogacy, and remaining childless. Whilst PGD was the preferred choice for these patients at this time in their lives, they understood very well that this might change—for reasons related to age, finances, emotional energy to cope with failure, and/or technical reasons to do with gametes and/or embryos.

The choice to undergo PGD then, is always temporally specific—couples undertake this choice now, but may well make other choices in the future. But it is also a choice couples consider in relation to the longer-term future, and in relation to the passage of time. Some young couples we interviewed discussed the possibility of returning to PGD in the future, for example, when they assumed that the technique will be more advanced. This was true for Sally and Ben, who were considering adoption if their attempts at PGD ended in failure. As Ben told us, “If we say three attempts now, cause we're so young, and then we adopt, it's inevitable that we're at some point probably going to go for it again! . . . Especially in five years when the techniques are even more advanced and so on”. While the older couples we interviewed did not perceive themselves as having this option, many were thinking of alternative forms of reproductive assistance that might be possible for them to consider in the future.

The costs of choosing PGD

A risk of which both patients and PGD professionals are well aware is that the process of becoming engaged with PGD can have negative impacts on the possibility of pursuing other reproductive and life choices.⁴ Some couples, such as Sally and Ben, found it difficult that engaging with PGD meant that they could not simultaneously pursue adoption, for example (adoption agencies in Britain do not accept couples who are engaging with assisted reproductive treatments). Issues of both time and age were mentioned by couples we interviewed who worried that spending time undergoing numerous cycles of PGD might decrease their chances of being viewed as suitably young adoptive parents. Other interviewees expressed concern that pursuing PGD had the potential to consume most of their energy, time, attention, and finances. Many of the interviewees were concerned to limit their attempts at PGD in order to leave time and resources to devote to other aspects of their lives—including work, relationships, or travel. The spectre of “wasted” years lost to repeated failed attempts at reproduction was clearly

in view for many couples, particularly women, who felt that their careers and social lives were seriously disrupted by participating in PGD cycles. Sally described this feeling to us in terms of being “on hold”:

Sally: It’s putting your life on hold. I’ve got a big problem with career at the moment, because I feel that I can’t give my all to the job, because I’m not concentrating because I’ve got other issues at home! You know, I don’t want to be stressed out at work, travelling to and from, commuting every day. I want to be totally *relaxed* but then, I’m at home, [smiling] I’ve got a little part time job, I’m not doing anything career-wise and what happens if we don’t end up having children? What happens if things don’t go to plan, and we are childless? I’m not going to have a career to push myself into, because I’ve kind of put that on hold! And I keep thinking I’m really unsettled in my own mind about the future. I want a career, and I want to earn good money so we can carry on having IVF attempts, in *that* respect, but in the *other* respect I’d rather not be working and under pressure so we give the IVF a better chance.

This sense of not knowing what the near future holds makes Sally’s life difficult, especially when she sees her friends planning their families and careers. “In a year’s time”, she said, “I don’t know if I’m going to be pregnant, if I’m going to have a child, if we’re going on the adoption waiting list”. Sally was also aware of the gendered implications of this scenario, in that the impact on her life of waiting to see if PGD would be successful was greater than for her husband Ben. She continued,

And this is something that I find *really* hard to come to terms with and no disrespect to Ben, but like it’s easier for him because he can go to work as normal, because he can forget about it! I think it’s a bit different for men. I’m the one that’s having the injections. I’m the one that’s getting the hormone treatment. He can go to work and kind of switch off a little bit, whereas I’m the one that’s thinking ‘I’ve got to be at home. Got to try and relax’.

Sally’s description of her predicament, like many other comments from interviewees, stands in very acute contrast to media representations of elite couples seeking a “designer baby” to complement their wealthy lifestyles. The new “reprogenetic” choices offered to couples like Sally and Ben are far from easy or straightforward, and demand significant emotional and mental labour on their part, as well as physical discomfort and/or pain for the women (and sometimes also the men). These techniques are also rightly perceived to involve a range of risks, including risks to health, relationships, careers, and financial security. Patients assess the multiple costs of PGD

on an ongoing basis, planning ahead and thinking about the impact of each treatment cycle on themselves, their partners, and their families. In sum, we found the patients we interviewed engaged in complex equations about their personal and reproductive futures, in which a very wide range of variables and considerations were seen to be at stake.

Conclusion

The HFEA/HGC joint working party stresses that the scientific and medical technologies associated with PGD are continually changing and that the regulatory framework will consequently need to be kept under review (HFEA/HGC, 2002: 9). We suggest that a similar statement could be made about the social and ethical aspects of PGD. Society or “the social” is constantly in process and any analyses of social understandings need to be “kept under review”. It is common in the area of the new genetics for commentators to claim that the science is “racing ahead” of public opinion and understanding, and that brakes need to be applied on scientific research so that we can catch up socially. Our ethnographic research provides an interesting counterpoint to this commonly encountered stereotype of “runaway technology”, with which the idea of the “designer baby” has become increasingly linked. As we have demonstrated, patients undergoing PGD do so with great sensitivity to the ethical and social issues at stake, and are for various reasons keenly attentive to, and concerned with, these issues. Their accounts are often highly nuanced, for example in the ways they both draw upon and distance themselves from the discourses of reprogenetic choice through which PGD is primarily defined. When describing the choices they make, we found the PGD patients participating in our study were at pains to emphasise that while they felt fortunate and grateful to undergo PGD, their choices were neither simple nor trivial. To the contrary, their reproductive choices required careful thought and thorough consideration of the many issues at stake, both personally and socially.

Our wider ethnographic study suggests that the social and ethical dimensions of the new genetics in the context of reproduction are not only issues of which patients are very aware, but that they are prominent within the clinics and labs as well (Franklin & Roberts, 2002). All of the relevant participants in what one patient aptly called “the topsy-turvy world of PGD”, including patients, clinicians, scientists, social scientists, lobbyists and policy makers, are actively engaged with its social and ethical aspects, and indeed are in a constant process of redefining what these are. This multiplication of “ethical” dimensions means that there

will never be a time in which “society” can finally determine the conditions under which it is and is not acceptable to offer the choice of PGD. Like the scientific and clinical technologies associated with PGD, social and ethical understandings of PGD are multiple and in a continual state of refinement.

The interview data discussed in this article demonstrates that new forms of choice involved in PGD are contextually specific. These choices are situated in historical time and geographical and social space, as well as within the lifecycles and social worlds of particular individuals and couples, making the concept of “abstract” or “objective” genetic information problematic. The existence of technologies such as PGD enables new forms of reproductive choice based on genetic information, as well as the possibility of making these choices before a pregnancy is established, but these choices are neither simplified nor made easier as a result. Indeed, PGD offers choices that can be experienced as an obligation, an opportunity, or “not a choice at all”. In addition, these choices must be negotiated in relation to a complex network of other choices, conditions, and possibilities.

Ethnographic research demonstrates the complexities of the phrase “reproductive choices” and illuminates the ways in which such choices are not abstract issues, but lived, embodied, practical, technical and social experiences—activities, in other words, that people undertake in interaction with others. As discussed earlier, this kind of social scientific research does not produce answers to ethical or social questions, but rather by producing detailed descriptions, leads to further, more nuanced questions. In terms of analysing PGD as a new form of reproductive choice, then, we conclude with a set of new questions arising from the analysis undertaken here: What is the relationship between choices and obligations in the context of PGD treatment? How do patients and clinicians define the “ethical” dimensions of treatment? Do the new choices associated with PGD create new burdens for would-be parents? How do patients negotiate these new burdens, and how can clinical practice become more sensitive to them? Who refuses PGD treatment and why? What are the long-term implications of failure for PGD patients? What can PGD patients tell us about the strategies they use to make difficult decisions and cope with the challenges of treatment? The data we have discussed here provide some indicative means of considering these questions, but further empirical documentation will be necessary in order to establish an effective comparative and longitudinal basis for more conclusive findings. The ability of social scientists and clinicians to work effectively together with patients in the pursuit of these questions will be at a premium in the effort to

create more robust accounts of the social, personal, and ethical stakes at issue in the context of new forms of reproductive choice.

Notes

- 1 We would like to acknowledge the generosity of the staff and patients of these two clinics. In particular, we would like to acknowledge the contribution of the two clinical directors, Professor Peter Braude (London) and Mr Anthony Rutherford (Leeds). This study would not have been possible without their interest and support.
- 2 Our consent procedure for interviews was approved by the Research Ethics Committees of both hospitals, as was a patient information sheet explaining our study and our methods. We asked patients to agree to be interviewed and for the interview to be transcribed on the understanding that (1) they could be given copies of the tape or transcript and (2) that the tapes would be destroyed following completion of the study.
- 3 It may not be feasible at this stage to expect couples to completely rethink their options, or to alter their views after discussing what it means to have a genetically affected child. This is problematic in terms of the joint working party’s recommendation that the seriousness of the genetic condition and other options be discussed with the clinical team when couples arrive at the PGD clinic (HFEA/HGC, 2002: 6–7). Such discussions may actually need to occur in other sites prior to this arrival to be effective.
- 4 Many of these impacts are similar to those experienced by couples undergoing standard IVF treatment (see Franklin, 1994).

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