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‘What is the role of reduced IVF fees in persuading women to volunteer to provide eggs for research? Insights from IVF patients volunteering to a UK ‘egg sharing for research’ scheme.’

Erica Haimes and Ken Taylor

SUMMARY:

This article reports selected findings from a project investigating the question: ‘Does volunteering for the ‘Newcastle egg sharing for research scheme’, in which IVF patients receive reduced fees when providing 50% of their eggs, entail any social and ethical costs?’ The focus is on women’s views of the role of the reduced fees in persuading them to volunteer. The study fills a gap in knowledge, as there have been no previous investigations of women’s experiences of providing eggs for research under such circumstances. This was an interview-based study, designed to gain understanding of the volunteers’ perspectives. The main findings are that the interviewees’ primary goal is to have a baby; they volunteered to provide eggs for research in order to access cheaper treatment in a context where private IVF fees are high, there is insufficient state funding, and providing eggs for other couples’ treatment was deemed unacceptable. Interviewees welcomed the scheme, but were not volunteering entirely under circumstances of their choosing; they would prefer not to provide eggs during their own IVF treatment and under certain circumstances change their minds about so doing. In conclusion, reduced fees, although an important factor, do not act as an *undue* inducement in persuading volunteers to act against their own interests.

Introduction

The growing demand for human eggs for research has provoked numerous debates over the social and ethical challenges involved in acquiring those eggs (Mertes & Pennings, 2007; Haimes et al., 2012). One question has attracted much attention: should women providing eggs for research be

given any return, either for their eggs or for the interventions and possible risks involved in providing eggs, or would such returns constitute an undue inducement (Egli et al., 2011; Roxland, 2012)? The ESHRE Task Force on Ethics and Law (Pennings et al., 2007) endorsed modest compensation to IVF patients providing eggs for research.

These debates are rarely informed by the views of women volunteering to provide eggs under such circumstances (Klitzman & Sauer, 2009) or by other empirical evidence (Braun & Schultz, 2012). The study reported here addresses that gap in knowledge by investigating the views of IVF patients volunteering to the 'Newcastle egg sharing for research scheme' (NESR). In this scheme, run by the Newcastle Fertility Centre (NFC) and established to provide fresh eggs for nuclear transfer (NT) research, egg providers receive a reduction of £1500 in fees for a cycle in which they provide eggs; full fees are approximately £3,700 (NFC, 2012).

At the time of our study, the terms of the NESR were: (i) volunteers came forward as potential egg providers in response to media coverage or to reading information leaflets at the clinic; clinicians could not ask them for eggs directly; (ii) women should have had IVF previously to confirm such treatment is required and to indicate the likely number of eggs they would produce; (iii) women should be aged 21-35; (iv) the consenting process must be conducted by an independent research nurse; (v) if women produced six or more eggs, they kept 50% and researchers received 50%, allocated one-by-one, on retrieval; if women produced five or fewer eggs they kept them all and still received the discount; if women produced an odd number of eggs the extra one was retained for treatment; women could choose their own, higher, number of eggs before the agreement was triggered; (vi) women could change their minds at any time up to egg retrieval but had to pay the full fees.

The NESR was considered controversial and the Human Fertilisation and Embryology Authority (HFEA) only licensed it fully in February 2007, after a public consultation (HFEA, 2006). The UK Medical Research Council (MRC) then funded the NT research at the NFC, including the discount to

egg providers. The MRC also funded the present independent study to address the question, ‘does volunteering to provide eggs for SCNT research, in exchange for reduced IVF fees, entail social and ethical costs?’ We prefer ‘provision’ as a more neutral term than ‘sharing’. We addressed our key question through a number of subsidiary questions. The focus for this article is women’s views on the role of the reduced fees in persuading them to volunteer for the NESR in the first place.

Methods

Our project received full approval from the local research ethics committee. We are employed at the same university as that to which those establishing the NESR are affiliated; however, our project, though conducted with the full co-operation of the NFC, was an independent study. We recruited a Project Advisory Group to assist in maintaining analytical objectivity; this included a senior scientist with a public record of opposing the NESR and SCNT research using human eggs.

This was an interview based, qualitative, inductive study, designed to understand the perspectives of NESR volunteers. Since the goal was to evaluate whether *volunteering* created any social and ethical costs all women who had volunteered for the NESR were approached. This included women who went on to provide eggs, women who withdrew after being accepted, and women who were not accepted; it was considered important to know whether those who withdrew had done so because of reservations about the scheme and whether those who were rejected suffered in any way from that rejection. All NESR volunteers were contacted by letter, sent via the NFC, requesting their participation in an interview; those who agreed returned a signed consent form to us (thus protecting patient confidentiality). Volunteers who had had recent IVF were contacted six weeks after their pregnancy test results. A total of 246 letters were sent which resulted in 25 interviews with IVF volunteers; a response rate of 10.2%. At the time of interview, 7 of the 25 had been accepted for the NESR and had provided eggs; three were accepted but withdrew and 15, some of whom had been rejected as unsuitable, did not progress beyond the early stages. The NFC reported

that 265 women applied for information about the scheme; 112 met the criteria; 42 went on to provide eggs and 7 women withdrew consent (Choudhary et al., 2012). All interviews were conducted by the lead author, enabling ongoing analysis and progressive focusing; all were fully transcribed. A hermeneutic analysis of transcripts was conducted, reaching thematic saturation, then constant comparison and category-building procedures followed by category mapping were used to identify major patterns and relationships in the data (Silverman, 2001).

A further 42 interviews with other groups were conducted for a range of comparative purposes, but, for reasons of limited space, the focus here is on the 25 IVF volunteers and the influence of the reduced fees on their decision to volunteer in the first place.

Results

Whilst the interview aide-memoirs were wide ranging in their coverage of topics, interviewees repeatedly returned to their wish for a baby as the central explanation for their views and actions. It was clear from the interviews that, before volunteering, every woman/couple considered the impact that participation in the scheme would have on their chances of success. They weighed the possible costs of providing 50% of their eggs to research against the possible benefits of receiving a reduced price IVF cycle.

(i) Providing 50% of their eggs: This was a significant consideration for all interviewees:

'... it's not something that somebody who wasn't producing a lot [of eggs]... could think about, because it's halving their chances, but because I produce a lot it wouldn't really be halving my chances' (M02).

Most interviewees, including all seven who provided eggs, reported having 'lots' of eggs in previous cycles, ranging between 17 and 46. Those who had had previous IVF knew that the relationship between the numbers of eggs, numbers of viable embryos and the likelihood of a baby could be

complex (described elsewhere as the ‘calculus of conception’ (Haimes and Taylor, 2009:2144)). One interviewee said, *‘we tried to do it statistically’ (M10)* using the numbers of eggs and embryos from their previous cycle to decide the minimum number of eggs they wanted to produce before triggering the NESR arrangement. However, *‘you never know’ (M05)* how many eggs will actually be produced.

Contemplating the possibility of providing 50% of their eggs to research was made easier by the terms of the NESR:

‘[It] was reassuring to know that if you did have a small amount you weren’t going to lose half of the small amount that you actually had’ (M03).

Similarly, the right to withdraw was important:

‘We made a decision that if we only had a certain amount of eggs that we wouldn’t go through with it because we felt it would drastically reduce the chances [of pregnancy]’ (M10).

‘You can always change your mind if you’re bordering on seven, eight and you don’t want to risk it. But you do have to pay the full amount!’ (M07).

Interviewees therefore combined their previous experience of IVF with knowledge of the safeguards built into the NESR, to try to judge the level of risk to their chances of having a baby that providing 50% of their eggs would entail. However, the calculations were not easy because of the uncertainties inherent in IVF treatment.

(ii) Views on the reduced fees: Interviewees’ views on the reduced fees were tied to their concerns about the affordability of private IVF fees and their views about insufficient state funding for IVF. They indicated that as soon as the possibility of IVF arose, they had started thinking about how to manage the costs, long before they heard about the NESR.

‘money is the thing with IVF, unfortunately, that’s what it boils down to’ (M21).

(a) Private fees: Almost all interviewees complained about private fees, describing them as *'a hell of a lot'* even when half price (M16); *'really expensive'* (M28). One suggested that clinics are dealing with *'captive audiences'* so can charge what they want (M01). Interviewees were also worried about just how high the fees would eventually become since, when they embarked on treatment, they did not know how many cycles they would need or what procedures and drugs would be required.

Family assistance in meeting the costs was common.

For several interviewees the NESR offered the chance of a cycle that otherwise would not have been affordable:

'We would not have been able to do another cycle then if we didn't have the assistance of the egg sharing scheme... People [who] say it's not the best way to actually get the eggs... don't know the position the people [who] are struggling for children are in, [who] can't afford another private cycle and have to wait a long time on the NHS waiting list.' (M03)

'Financially [IVF] nearly ruined us the first time ... this would have been probably our last go, financially and emotionally. But we didn't have the money for a full treatment' (M06).

There was no direct relationship between interviewees' sense of the affordability of any/further IVF and their income levels. Interviewees reported annual household incomes ranging from £15,000 to over £70,000, with an average of £45,468; the average household income for north east England, where the NESR is based, was £28,600 in 2008 (Office for National Statistics, 2011) when the fieldwork was started. The seven volunteers who provided eggs were amongst the higher earners, with an average household income of £50,786. Interviewees with higher than average incomes were no more convinced they could afford private IVF than those on lower incomes, because they felt the same uncertainty about the eventual cost of successful treatment.

(b) State funding: The problem of limited National Health Service (NHS)-funded IVF was raised by every interviewee and was coupled with the costs of private treatment in influencing them to volunteer for the NESR. UK national guidelines recommend that IVF patients who meet locally set

criteria should be allowed three cycles of NHS-funded treatment (National Institute of Clinical Excellence, 2004); a level of provision that places the UK amongst the lowest providers of state-funded IVF in Europe (Photopoulos, 2012). Approximately 75% of health regions in England and Wales do not provide even that (All Party Parliamentary Group on Infertility, 2011). However, NHS funders in the region in which the NESR is based agreed to meet those guidelines, as a result of lobbying by various parties, including the NFC. This additional access was welcomed by interviewees as *‘that gives us a bit more comfort, thinking “well, if it doesn’t work this time I’ve still got one more [NHS-funded] chance”’* (M23).

Interviewees did not argue for unlimited access to NHS-funded IVF and acknowledged the difficulties in establishing eligibility criteria. However, they were troubled that NHS funding was usually not available if one partner already had a child:

‘From an NHS point of view I would have had to go through life without having somebody really close to me being little and seeing them grow up, because [partner] had two grown up children’ (M24).

Interviewees’ preference for receiving more NHS funding over volunteering for the NESR was clear: *‘I would prefer the NHS waiting list was not so long [as] that would be my first option and I always wanted [the NESR] to be a last option’* (M17). One woman angrily said that people who do not approve of the NESR should, *‘give me as much [NHS] treatment as I need and then you can have some of my eggs for research, but if you won’t give me the free treatment then at least give me reduced fees so you can have the eggs’* (M03).

Several interviewees suggested a reciprocal arrangement between NHS funding and providing eggs for research: *‘If I was getting NHS help they could have had my eggs for nothing’* (M20).

(c) ‘Money isn’t everything’: In light of the expense of private treatment and the difficulties of accessing NHS-funded treatment, the reduced fees were clearly important. However, interviewees were cautious about allowing the discount to determine their actions. It was *‘not the be all and end all, but... unless you’ve got an endless pot of money, it is a consideration’* (M19). One couple needed

‘to weigh up the cost saving and what you’re doing it for... Money isn’t everything, success is everything... Whilst you’ve got to take finances into account, you... don’t want to limit any chance of success’ (M01).

A couple who changed their minds about providing eggs said, *‘we started out thinking “financially this is a great idea”, morally we agreed with it and then... when we didn’t have that many eggs... we felt, “we don’t care about the money, we should keep all these eggs...”’ (M10).*

(iii) Other financial considerations: Space constraints prevent a detailed presentation of data on all aspects of interviewees’ views but it is useful to add a brief summary of their views on other financial matters that arose in debates about egg provision since these contextualise their views on the influence of reduced fees. For example, interviewees knew they could have volunteered to provide eggs to other couples, receiving almost free treatment in return. However, only two women had done so; others rejected that option, as most found contemplating another woman having a child with their eggs, when they were unable to do so, too emotionally difficult. Interviewees also had little interest in alternative ways of calculating the discount, such as a ‘fee per egg’. This was rejected outright by every interviewee as unfair, putting undue pressure on women to produce a lot of eggs in order to secure a reasonable reduction, when they had no control over how their bodies would respond. Interviewees also rejected the possibility of receiving cash instead of a fees discount as *‘That makes it all about money and it shouldn’t be, it should be about the fact that somebody wants a baby’ (M04).* Interviewees also showed no interest in determining the amounts of money in the discount, or for setting minimum and maximum amounts, because they judged the value of the discount in relation to the number of extra chances of treatment that it would provide, when calculated against full IVF fees, rather than as a sum of money in its own right.

We asked interviewees whether they considered themselves to be selling their eggs. Many rejected this interpretation; others were less sure, but argued that since the arrangement was part of an established treatment, by an approved clinic, and undertaken to assist research, it was acceptable:

'It does sound like [egg selling]. Well, it is... because they're giving you the money for the other half of your treatment... but as long as it's to a good cause... I wouldn't go on the internet and sell them but I was only up for doing the egg sharing because it was the NHS who are involved in the [clinic]... and I knew it was a professional place' (M18).

When asked if they would provide eggs for no return at all, almost all interviewees said they would happily consider this, *if*: the eggs were not suitable for treatment or were 'surplus' (however defined) to their own needs, or if they had had a baby, or had decided to end treatment. Unless such circumstances arose they could not 'give eggs away' as, *'I've still got that tiny bit of hope so I need whatever's there!'* (M21).

One woman summed up many of the distinctions that others made about the reduced fees:

'It's not about the cash, it's about getting treatment or maybe being able to afford another cycle... because your fees have been reduced. [It's] your means to an end that is hopefully pregnancy' (M19).

In the final section of the interview we discussed with interviewees their overall evaluation of the NESR. The overwhelming response from all interviewees, whether accepted or rejected for the scheme, was very positive and summed up by one individual, *'I would [volunteer] again, definitely. No regrets at all'* (M06).

Discussion

The interviewees' goal was to have a baby and they viewed the NESR as a means to achieve this, by providing access to cheaper treatment. The reduced fees were clearly important to most interviewees, who had little or no access to NHS-funded treatment and for whom private fees were

too high, either to afford at all, or to afford without anxiety. Most volunteers would prefer not to give 50% of their eggs to research as a means of accessing cheaper treatment and only contemplated doing so because their previous experience of IVF indicated they would have what they considered to be enough eggs and because they could change their minds up to the point of egg collection. This suggests that previous IVF is not just useful in estimating a woman's likely response to ovarian stimulation, but is also important in helping volunteers make better informed decisions about participating in the NESR (Haimes & Taylor, 2009). However, volunteers did not proceed with the NESR if they did not need it to access further treatment (e.g. because more NHS treatment became available) or if they considered the risk to their chances of having a baby, through providing 50% of their eggs to research, as too high. Neither did they volunteer to provide eggs to other couples despite the much larger reduction in fees that it would entail. These observations suggest that although the reduced fees could be considered an inducement, they do not act as an *undue* inducement, persuading volunteers to act against their own interests (Hyun, 2006).

Discussions about other ways to organise the financial aspects of the scheme, such as 'fees per egg' and different levels of discount, suggested that interviewees did not volunteer for the NESR with ideas of what their eggs were worth or wishing to negotiate terms. They simply wanted (more) treatment. This suggests that the NESR might be better regarded as an 'egg exchange' scheme, where eggs are exchanged for treatment, rather than an 'egg sharing' scheme.

Overall, although interviewees warmly welcomed the NESR, most would prefer to finish their IVF treatment and then offer eggs to research as they would not then have to worry about the impact of giving up 50% of their eggs on their chances of pregnancy. Although they regarded themselves as making their own decisions about volunteering, one could argue that they were not volunteering entirely under circumstances of their own choosing (Haimes et al., 2012), especially given the fact that the NESR introduced yet more uncertainties into their already uncertain experiences of IVF. However, this finding should be considered alongside the NFC's own analysis (not available at the time of the interviews) of the impact on its 42 egg providers of providing eggs (Choudhary et al.,

2012), which indicated that the live birth rate for egg providers was 37.3% and 29.4% for matched patients, per treatment cycle started. This reduced the uncertainty about the effects of participating in the NESR and provided reassurance for future volunteers.

Clearly it would be valuable to compare the present findings with those of other studies. However, there are no directly comparable empirical studies of the experiences of IVF patients volunteering to provide eggs for research in exchange for reduced IVF fees. The closest such study comes from Carroll and Waldby (2012) who discussed the possibility of providing eggs to research with IVF patients in Australia and found they would be reluctant to do this. This was a hypothetical discussion and further research is needed to establish whether patients with access to more state funded or cheaper, private, IVF than our interviewees, are as willing to volunteer to provide eggs for research under schemes that offer reduced fees.

Our study provides valuable evidence for policymakers, ethicists, clinicians, scientists and patients, to assist their deliberations and practices around the acquisition of human eggs for research, including in the expanding field of mitochondrial research (HFEA, 2011; Nuffield Council on Bioethics, 2012). These findings are being presented at a time when the HFEA has approved payment of expenses incurred, of up to £750, when providing gametes for treatment or research (HFEA, 2012) and when the Nuffield Council on Bioethics (NCoB) has recommended a pilot scheme be conducted to assess the effects of offering financial compensation to non-IVF egg providers (NCoB, 2011:209-210). These initiatives suggest that the question of how best to organise the provision of gametes for research is still open to debate. In the light of our study, we suggest that further research is needed to compare systematically the different populations of potential egg providers (IVF patients, non-IVF women, ex-IVF patients), for different purposes (treatment or research), under different compensation schemes (Egli et al., 2011), to identify the full range of motives of potential providers, and the socio-economic contexts in which they volunteer, in order to assess further the costs and benefits to providers (Ballantyne & de Lacey, 2008; Waldby, 2008).

In the meantime, whilst this study provides valuable empirical data in a field that has lacked such information hitherto (Braun & Schultz, 2012), caution needs to be exercised in interpreting the interviewees' positive endorsement of the NESR as a mandate to extend compensated 'egg sharing for research' schemes worldwide for IVF patients or as a mandate for compensating non-IVF women for providing eggs. The NESR was welcomed by IVF patients because of its safeguards and because of its position within the financial landscape of IVF provision in the UK. The main lesson to be learned from this study is that the growing use of eggs in research needs to be accompanied by awareness of the socio-economic position of the women being asked to provide eggs and by engagement with the views of such women, to ensure that they receive effective ethical protection.

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Declaration of interest: Possible conflicts of interest: In order to achieve complete transparency, the authors have explained in the text that they are employed by the same university as that to which those who established the scheme under scrutiny (the 'Newcastle egg sharing for research scheme') are affiliated. However, the work reported here was funded by the MRC as a completely independent study, following external reviews. A Project Advisory Group of senior UK colleagues was also appointed to assist in maintaining analytical objectivity. Erica Haines is a member of the International Society for Stem Cell Research Ethics and Public Policy Committee and of the Royal College of Obstetricians and Gynaecologists Ethics Advisory Board; she receives no financial return from either organisation. The authors alone are responsible for the content and writing of the paper.

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