TITLE: Being an identity-release donor: a qualitative study exploring the motivations, experiences and future expectations of current UK egg donors.

RUNNING HEAD: Experiences of UK identity-release egg donors

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Abstract

The objective of this study was to examine the motivations, experiences and future expectations of identity-release egg donors in the UK following the removal of donor anonymity and the rise in financial compensation for egg donation. This exploratory, in-depth qualitative study comprised semi-structured interviews with eleven women who had attended an egg donation screening appointment at a UK clinic during a four-month period in 2014, conducted two to six weeks after the woman had donated or had withdrawn/been rejected from the donation process. Participants' primary motivation for donating was to help infertile women have their 'own child', and the recent increase in financial compensation did not seem to play a significant role. All were happy to be identifiable and contacted by children born as a result of their donation. However, some were hesitant about providing non-identifying information about themselves for these offspring and wished for further information about the recipient(s) of their eggs and the outcome of their donation. Whilst this study was limited due to the small sample size, it is the first study of UK egg donors following the rise in donor compensation and suggests that other strategies may be more effective in increasing donor numbers.

Key words: egg donation; egg donor; identity-release donation; motivation; information provision; financial compensation.

Introduction

According to the Human Fertilisation and Embryo Authority's (HFEA) report on egg and sperm donation (HFEA, 2014), in 2013, 4% of the 48,477 fresh IVF cycles performed in the UK used donor eggs. The need for egg donation may arise for various reasons but for many women, it is poor egg quality associated with advanced maternal age that indicates the use of donor eggs. With childbearing in the UK now tending to occur at a later time in women's lives (ONS, 2013), it is likely that the demand for donor eggs will only increase.

In the UK, treatment with donor eggs can occur either through known donation, i.e., with the eggs of a woman who is known to the recipient at the time of donation, or through unknown donation. Known donors are usually friends or relatives of the egg recipient, but recently the growing trend for online connection sites enables those seeking donor eggs to meet women, previously unknown to them, who are willing to become a 'known' donor for them. Unknown egg donors may be patients, most commonly 'egg-sharers' (women who are themselves undergoing IVF treatment and choose to donate a portion of their eggs in exchange for reduced treatment costs) or non-patient donors. Since the removal of donor anonymity in 2005, the identity of the donor will be released upon request to any resulting offspring once they reach the age of eighteen.

In 2011, due to a perceived shortage of UK gamete donors, the HFEA launched a public consultation into gamete donation (HFEA, 2011). One of the goals of the consultation was to find ways to increase the numbers of new donors registering, and to maximise the use of their gametes. As a consequence of the consultation, in April 2012 new limits for donor compensation were introduced, moving away from a system of

out-of-pocket expenses and a loss of earnings allowance capped at £250, to one where sperm donors are given a fixed sum of £35 per clinic visit and egg donors receive a fixed sum of £750 per donation cycle, including expenses.

Payment of egg donors has long been a controversial issue (Pennings et al., 2014; Pfeffer, 2011), raising concerns regarding exploitation of women in financial difficulty and commodification of the human body, as well as how a donor-conceived child may feel about being conceived with the aid of a monetary transaction. The HFEA's online survey exploring UK clinics' thoughts regarding how the new donation policies were working and their impact on practice (HFEA, 2014), found that the number of women expressing an interest in donating eggs had risen since the increase in compensation. The number of new non-patient egg donors actually registering with the HFEA (i.e. going through with egg donation) has also increased. In 2011 there were 815 new registrations, rising to 1103 in 2013. The rise in new donor registrations was attributed to the higher levels of compensation available to donors, as well as increased awareness and marketing (HFEA, 2014). However, the most common reason clinics gave for egg donors' motivation was the desire to help others.

Studies from contexts where women donate their eggs in a commercial setting indicate that motivations appear to comprise a mixture of altruism and financial compensation (Kenney and McGowen, 2010; Klock et al. 1998, 2003; Purewal and van den Akker, 2009). Patrick et al. (2001) found that US commercial¹ donors believed

¹ Terminology within the field of gamete donation is complex and, at times, controversial. Purewal and van den Akker (2009), in their systemic review of egg donation describe 'non-patient donors' as including different subtypes: volunteer donors (donation without financial reward), known donors (donation to known recipients), commercial donors (donation with monetary compensation) and potential donors (whom report an intention to donate their oocytes). However, it is often not easy to so clearly define donors. A woman receiving \$5000 for donating her egg in the US may not see herself as a commercial donor but as someone helping another woman

financial compensation was necessary to recompense the hardship they endured and that most donors would not donate if payment was not provided. Similarly, Kenney and McGowen's (2010) survey of 80 women who had previously donated eggs in the US found that although their motivations to donate were complex and intertwined, the majority (73.8%) reported that financial compensation played a significant role in their decision to donate. By contrast, donors not receiving monetary compensation describe generally altruistic motivations, along with experiences of infertility, either personally or amongst family or friends (Fielding et al., 1998; Byrd et al., 2002). Other motivations reported in the literature include confirmation of one's own fertility (Jordan et al., 2004) and to pass on one's genes (Kalfoglou and Geller, 2000), as well as making up for a loss, such as a past abortion or miscarriage, or rape (Purewal and van den Akker, 2009).

Pennings et al. (2014), in their survey of the socio-demographic and fertility-related characteristics and motivations of 1423 egg donors in eleven European countries with varying compensation schemes, found that 47.8% of egg donors reported being motivated by altruism alone, 33.9% were financially and altruistically motivated, 10.8% purely financially motivated, 5.9% motivated by altruism and their own treatment, and 2% motivated by their own treatment only. Motivation to donate was found to vary according to a donor's age, employment status and educational level (Pennings et al., 2014). In the subgroup of 116 UK donors, reported motivations were

to have a baby (see, for example, Almeling, 2011). Moreover, due to the change in compensation system in the UK whereby egg donors now receive a set sum for their donation, it is unclear which subgroup these donors would be defined under: does their monetary compensation negate the 'volunteer' aspect of their donation and instead mean they are commercial donors? Daniels and Lewis (1996) go as far as disputing the term 'donor' when women are paid for their eggs and suggest it should instead be replaced with the term 'provider'.

30% altruism, 20% own treatment, 47.3% altruism and own treatment, and 2.7% altruism and financial. No egg donors reported financial motivation only. It is important to note that 78.4% of the UK donors taking part in the survey were egg-sharers and the authors did not break down their results into patient and non-patient egg donors. Egg-sharers who are themselves undergoing IVF in the pursuit of parenthood may well be differently motivated to women donating eggs who are not, at that time, undergoing fertility treatment.

Klock et al.'s (2003) survey of US commercial egg donors found that those donors who went on to become repeat donors rated financial compensation as more important to them than those women who only completed one cycle. However, regardless of motivation, studies have found that donors report high levels of satisfaction with the egg donor procedure and when questioned, most egg donors state that they would donate again (Purewal and van den Akker, 2009).

It is unclear how changes in legislation regarding donor anonymity may have impacted upon what it means for women to be an egg donor. Svanberg et al.'s (2012) questionnaire study of identity-release gamete donors in Sweden, the first country to remove donor anonymity, found that altruistic motives and awareness of the distress and sorrow of being childless were the most common reasons reported for becoming an egg donor. Sixty-nine percent of the 181 egg donors who participated in the study had biological children (Sydsjö et al., 2011) and this motivated them to want to help other couples experience parenthood. However, a study of UK gamete donors' views regarding the removal of donor anonymity found that half of the 75 egg donors who completed the survey would not continue to donate if their anonymity was removed (Frith et al., 2007). Interestingly, despite donating under identity-release legislation, 15.5% of the UK egg donors completing Pennings et al.'s (2014) survey indicated that

they would be anonymous to the future child. The authors gave several possible explanations for this surprising finding: either counselling did not make this point clear to the donors or the respondents had misunderstood the question. A possible explanation that the authors did not note is that although at the time of donation egg donors agree to their identifying information being released to offspring at age eighteen, they have no intention of being available, or contactable, to these offspring at that time. Indeed, very little is known about how donors who have donated under an identity-release system think about their donation and future information exchange. A Swedish study (Isakkson et al., 2014) reported that 65% of identity-release egg donors surveyed 5-8 years after donating were positive towards being contacted by offspring once they reached the age of 18, with a further 17% being neutral towards this prospect, and only 2% stating that they did not want to meet a child conceived through their donation. It is not clear how UK donors think and feel about signing up to be an identifiable donor, how they interpret the legislation and how they envisage their future role.

The present study provides an in-depth insight into the perceptions, experiences and future expectations of current identity-release egg donors in the UK. It is the first study to explore UK egg donors' thoughts and feelings about being an identity-release donor and the impact of the increase in financial compensation on their willingness to donate.

Materials and Methods

140 This paper reports findings from an in-depth, exploratory study of non-patient identity-
141 release egg donors donating their eggs at a private clinic in London. The study was
142 granted ethical approval from the University of Cambridge Psychology Research Ethics
143 Committee (ref: Pre.2013.124). All women who attended a screening appointment at
144 the Clinic between January and April 2014 were eligible to take part in the study and
145 were given an information sheet and asked if they were happy to be contacted about
146 taking part. Twenty-three of the 29 egg donors (79%) approached agreed to be
147 contacted. Egg donors were contacted at the time they started hormonal stimulation or
148 when they had withdrawn or been rejected from the egg donation programme. Of the
149 23 egg donors who had agreed to be contacted, 11 were interviewed (of the others, 3
150 were not contactable, 3 initially agreed to participate but were unable to be interviewed
151 at a suitable time, and 6 were still waiting to be 'matched' with an egg recipient and
152 begin the egg donation process at the end of the data collection period).

153 Semi-structured interviews were conducted with the egg donors between two
154 and six weeks after egg collection, or after their withdrawal/rejection from the egg
155 donor programme. As well as exploring the participants' own 'story' of their experience
156 of becoming and being an egg donor, the interviews covered how they first heard about
157 egg donation, their reasons for donating their eggs, their experiences of recruitment,
158 counselling and the medical procedures they had undertaken, and whether they had
159 discussed egg donation with others. The interview also explored the participants'
160 thoughts and feelings about donating their eggs, including thoughts and feelings about
161 the individual or couple who would receive their eggs, the child who may be conceived
162 as a result of their donation and possibilities for future information exchange. The
163 participants also completed the following questionnaires to assess their mental health:
164 The Edinburgh Depression Scale (Cox et al., 1987), the Trait Anxiety Inventory

(Spielberger, 1983) and the Rosenberg Self Esteem Scale (Rosenberg 1989) to assess anxiety, depression and self-esteem respectively. They also filled out short questionnaires about their motivations and experiences of egg donation² and their demographic background.

All interviews were carried out by one researcher (Susanna Graham) and took place at a time and place convenient for the participant (in the Clinic, their own home or a public space such as a café). The interviews lasted approximately 90 minutes and were audio recorded with the participants' consent. The interviews were transcribed verbatim and inductive thematic analysis (Braun and Clark, 2006) performed. This analysis was an iterative process, consisting of familiarising oneself with the data, memo writing, initial coding of the data, subsequent combining, expanding and collapsing of codes in order to construct themes that were grounded in the data. The analysis was performed with the aid of the computer software, Atlas-ti. This paper provides an overview of the most salient themes that emerged from these women's accounts of becoming and being an egg donor.

Results

Egg Donor Characteristics

Eleven participants, all living in the UK, took part in the study. Eight had completed an egg donation cycle. Three had to stop before egg collection: one was rejected due to low ovarian reserve, and two were awaiting rescheduling of their donation cycle due to

² These questionnaires were completed to allow for comparisons with other studies. The results do not inform the analysis in this paper.

personal or medical reasons for being unable to get to egg collection. It was the first time each participant had donated her eggs. The participants ranged in age between 18 and 30 years with a mean of 25 years. Five participants identified their ethnicity as White Other (Polish), four as White English/Welsh, one as Asian Indian and one as Asian Bangladeshi. Six participants stated that they had no religion, four were Christian and one was Muslim.

All participants identified as heterosexual. Six were single whilst five reported being in a relationship (two married, three cohabiting). Four participants had their own children. Of the seven women who did not have children, five were definite that they would like children in the future, one thought it most likely that she would have children and one was unsure.

Three participants were educated to GCSE level (or equivalent), two to A level (or equivalent) and six had a Bachelor's degree. Nine of the participants were employed (seven full-time, two part-time) in a range of occupations. One participant was a student and one a full-time mother. Eight participants reported no perceived financial difficulties whilst three said they were experiencing some/minor financial difficulties.

Individual scores on the Edinburgh Depression Scale (Cox et al., 1987), the Trait Anxiety Inventory (Spielberger, 1983) and the Rosenberg Self Esteem Scale (Rosenberg 1989), revealed that ten out of the eleven participants were within the normal range for depression, anxiety and self-esteem. The one participant who scored above the cut-off point for clinical problems was experiencing unrelated stressful life events at the time.

Becoming an egg donor

Eight of the participants starting thinking about becoming an egg donor after they saw or heard an advert for egg donation online or on the radio. A further three began to

213 consider egg donation as a possibility after hearing about it through friends or
214 colleagues. The majority (n=8) described having been previously unaware of egg
215 donation. They were aware that men could donate sperm to help people have children,
216 but had not realised this was scientifically possible for women.

217 The vast majority (n=10) of the participants discussed the possibility of donating
218 their eggs with others before they made the decision to proceed. All of the women who
219 were in a relationship (n=5) discussed the prospect of donating their eggs with their
220 partner. Six participants discussed becoming an egg donor with family members and
221 five with friends. However, all participants said that they were selective about who they
222 told about becoming an egg donor, with the majority wanting to keep this information
223 private between themselves and close family and friends. Reasons for not wanting to be
224 open about being an egg donor stemmed from fear of misunderstanding and being
225 judged, with ideas of relatedness, specifically that others may feel that they were “giving
226 away their children”, often at the core of this concern:

227

228 *I just didn't know what their reactions would be. I thought my sister would be*
229 *like, “Oh no, you shouldn't do that. It's your child. It's your egg”. And I guess*
230 *being Asian it is sort of just a different sort of cultural thing. My family aren't*
231 *like this but old fashioned Indians would be like, “That's part of my family. You*
232 *can't do that. You can't get rid of our children”. (Priya,³ 23 years old)*

233

³ Pseudonyms have been used throughout this paper and any potentially identifying information removed or altered.

234 Although this judgment was often attributed to religious or cultural differences, there
235 was also a general feeling amongst all participants that the decision to become an egg
236 donor should be a personal one.

237

238 *Motivations*

239 All participants described wanting to become an egg donor so they could help other
240 women to have their 'own child'. They described the pain and sadness they believed
241 childlessness would cause, and donating their eggs as something they could do to
242 relieve this pain for others. Eight of the participants knew someone who had been
243 personally affected by infertility and described this as a motivating factor, making them
244 think about donating their own eggs:

245

246 *It's all down to having seen first-hand both my aunties' struggles to conceive.*
247 *And being someone who has always wanted to have children, the thought of*
248 *being told that you couldn't have children must be soul destroying. So knowing*
249 *that that (egg donation), is out there, rather than just adopting or something,*
250 *so you can actually carry a child, I think that is great. (Rebecca, 23 years old)*

251

252 The four participants who had their own children wanted to enable others to enjoy
253 parenting as they themselves did. Six of the seven participants who did not have
254 children did not want children at that time and thought they could give another woman
255 who was struggling to conceive a chance to become a mother. Other reasons some
256 childless participants gave for wanting to donate their eggs included a means to check
257 one's own fertility (n=1), and as an alternative to having children oneself (n=1).

Although all participants described their main reason for donating eggs as helping others to have their own child, donating eggs was also seen as mutually beneficial: becoming an egg donor was seen as something that would also make them feel good about themselves:

It just made me feel like I was a good person and so instead of just wasting them I could give them to someone else and it just made me feel good. (Rachel, 23 years old)

Compensation

Despite concerns that the increase in egg donor compensation would result in women donating eggs for financial gain, none of the participants mentioned payment when asked why they had wanted to become an egg donor. When asked specifically about compensation during the interview, ten of the participants said that they would have still donated their eggs even if they were not going to receive any money. In fact, when first investigating the prospect of donating their eggs, ten participants were unaware that they would receive money:

When I first heard about it on the radio and started doing research about egg donation, I didn't know you received any money. So it was quite a shock but, yes, I guess it was nice to be paid for something that you were more than willing to do for free. (Rebecca, 23 years old)

Although the majority of the egg donors taking part in the study did not seem to have been financially motivated, when asked why they thought others became egg donors,

five said that they thought receiving money may play a part. Unease was expressed at women donating for money rather than for the “right reasons”:

I know there are people just doing it for the money and that is not good. If you want to do something then do it for free. (Emilia, 26 years old)

I think if you are making the choice to donate something then that should be your own choice and it shouldn't be about the money. (Claire, 30 years old)

Being an egg donor

Despite initial concerns about the health implications of becoming an egg donor, all participants reported that physically, as well as emotionally, donating their eggs was much easier than expected. Only three participants described experiencing pain and bloating during hormone stimulation or after egg collection, and although all had been warned that the hormones might make them feel emotional, only three participants described feeling “slightly hormonal”. The other participants described how, emotionally, they felt no different to normal, or, in one case, even “happier and more stable than usual”. Five participants said that donating their eggs had made things difficult in their day-to-day life but put this down to juggling clinic appointments with the demands of childcare and work commitments, rather than any specific procedures involved in egg donation. The difficulty in juggling work, childcare and being an egg donor was found to be particularly problematic towards the end of the egg donation process due to the frequency and unpredictability of ultrasound appointments to

307 monitor ovarian response, as well as the uncertainty regarding the date on which egg
308 collection would take place.

309

310 *Getting up there and back was pretty difficult. And obviously childcare and*
311 *things. And then you'd go up there and they'd say, "Right, we'll see you again in*
312 *three days' time." And then I'd be thinking, 'Argh, now I have to sort out*
313 *something else for (her child)'. I could imagine if you worked it could be really*
314 *difficult to do. And it's not like you can book it off in advance because you*
315 *literally don't know. They just say, "Come back on this day". So for working*
316 *people I imagine it would be really tricky. (Sophie 22 years old)*

317

318 With many of the participants only having told their partner, close family or friends,
319 that they were donating eggs, trying to hide clinic appointments added a further
320 burden:

321

322 *I had to attend the clinic for scans every two days and that was difficult to*
323 *juggle with work. I'd be late for work all the time and I had to make excuses*
324 *like, "I'm doing something" but I didn't want to say what it was I was really*
325 *doing because not everyone will understand this. (Anna, 28 years old)*

326

327 *And also you feel like you are hiding something all the time. Your friends are*
328 *asking you "What's going on? What is happening?" And I didn't want to tell*
329 *them so that was why it was quite hard sometimes. I would say something and*
330 *then I would forget what I had said. It's a shame but you are feeling like a liar.*
331 *So that is tricky. (Julja, 26 years old)*

332

333 *Donor information*

334 One other aspect of being an egg donor that the study participants identified as difficult
335 was providing non-identifying information about themselves in the form of a pen
336 portrait and goodwill message to donor-conceived children. This information is
337 included as part of the HFEA donor information form and can be accessed by a donor-
338 conceived child at the age of sixteen or by parents from the time they begin choosing a
339 donor. Only four of the participants completed the pen portrait and three of these
340 women also completed the goodwill message. These participants all described finding
341 these sections very hard to write, and five egg donors who did not complete them stated
342 that difficulty in knowing what they should write was a reason for not providing this
343 information:

344

345 *I wanted to but I couldn't really do it because I tried writing it but I kept on*
346 *referring to me, or not referring to me, but I could see that I was giving*
347 *something that was too personal. I found it hard to be objective about me*
348 *without referring to me. So that was the difficulty. (Agnieska, 18 years old)*

349

350 *I filled it (pen portrait) in but I didn't do a goodwill message. Erm, I don't*
351 *really know why. I think I just didn't know how to write it more than not*
352 *wanting to write it. I just found it a bit... weird? I don't know whether that is*
353 *the right word. I just didn't know what to write. (Claire, 30 years old)*

354

355 Reasons for not providing non-identifying information, or difficulty in knowing how to
356 do so, were, in the most part, associated with ideas of relatedness: the participants were

357 contemplating their role as an egg donor and what connection, if any, they had with a
358 child conceived with their donated egg. Ten out of the eleven participants
359 conceptualised their donation as “just an egg”, the start of a very contingent process
360 that *might* result in an ‘own’ child for the recipient of their egg.

361 In fact, it was concern and empathy for the recipient of their donated egg, rather
362 than thoughts about the donor-conceived child, that were at the forefront of four of the
363 participants’ minds when deciding not to fill in the goodwill message and pen portrait.
364 They thought such information would make them, as an egg donor, into a ‘person’
365 rather than the provider of “just an egg”. They believed such information would be
366 painful for the woman who would receive their egg to read:

367
368 *I was just trying to put myself in their position. So being in the position of the*
369 *mother that can't have a child in a normal way, natural way. So she's already*
370 *stressed and probably frustrated about that. So what's the point giving her*
371 *more things to worry about? I don't think it is necessary. Some donors maybe*
372 *write things for the child. Is it important? I think it is most important if this is*
373 *working out, yeah? If they are going to have the kids. So the woman can have*
374 *her own child. That is why I have done it. That's what is important for me.*

375 (Julja, 26 years old)

376
377 Six of the participants were concerned that providing non-identifying information about
378 themselves may place too much significance upon their role as an egg donor, specifically
379 that it may cause a donor-conceived child to reconsider whether the egg recipient was
380 their ‘real’ mother. Participants also asserted that a written description about
381 themselves would not give a child an accurate representation of what they were *really*

like. However, four participants stated that a child's ability to access non-identifying information about their egg donor was somewhat important, describing how, if told that they were conceived with donor eggs, a child might like to have some information about their donor. The one participant who thought non-identifying information was very important believed that such information would be essential for a child's identity formation.

Removal of anonymity

Despite the majority of the participants downplaying the significance of non-identifying information about themselves, all were happy to be identifiable to any offspring conceived with their donated eggs and to be contacted by the donor-conceived child from the age of eighteen. In fact all the egg donors stated that it was their "responsibility" to make sure they were available to answer any questions a donor-conceived child may have. Even so, four of the participants stated that they had concerns about being an identity-release donor. Interestingly, for three of these participants, these stemmed from concern for the donor-conceived child's parents - the egg-recipient and her partner – rather than herself:

I mean I think it might be quite hard for the parents because she has carried the child and brought it up and so yeah, I mean this could be quite hard if then their child wants to meet me. (Rachel, 20 years old)

Other concerns included the impact that a donor-conceived child making contact would have on an egg donor's own family (n=1), what the donor-conceived child might want from them, specifically the extent to which they may wish to form a relationship with

407 them (n=2), and a donor-conceived child's reaction to their egg donor, specifically
408 potential feelings of hurt and rejection (n=1).

409 Although all participants were happy to be contacted by a donor-conceived child,
410 the majority believed that this would be very unlikely to happen. They thought that
411 either the child would not be aware of their donor conception or that they would be
412 comfortable with this information and so would not feel a need to try to find out more
413 about their donor.

414
415 *Desire for further information*

416 All participants wanted to have more information about the outcome of their donation
417 than they believed was currently possible. Although all gamete donors who have
418 donated in the UK since 1991 are entitled to request information from the HFEA about
419 the number, sex, and year of birth of any people born as a result of their donation
420 (HFEA, 2014b), five of the egg donors did not know that they could receive information
421 about the outcome of their donation. Although all participants wanted further
422 information regarding the outcome of their donation, the egg donors varied in the type
423 of information they desired. Nine of the eleven participants said that they would like to
424 know whether the egg recipient had become pregnant and ten would like to know
425 whether there had been a birth. Six participants wanted to be informed about the health
426 and well-being of the baby, four wanted to know the baby's sex, three the child's
427 physical appearance and three the child's personality. Ultimately, all participants
428 wanted to know whether their donation had been "successful".

429
430 *And I would be interested to know how many births they got from it. I'd just be*
431 *curious and I'd like to know how many people I have helped and how many*

432 *babies have come from it and how successful it was. Just knowing that I did*
433 *actually make a difference and was it worth it to do it. (Sophie, 22 years old)*

434

435 It was not just the outcome of their donation where the participants desired further
436 information. Seven of the participants described wanting to know more about the
437 recipient(s) of their eggs and what these people were *like*. For two of the participants
438 this desire related to concerns about whether they would make ‘good’ parents, wanting
439 reassurance that any child conceived with their donated eggs would be brought up in a
440 ‘good’ home. The other five participants were not concerned about the recipient’s
441 parenting ability: they felt that anyone who was prepared to go through egg donation
442 was someone who “really truly, truly wants a child”. For them the desire for more
443 information was based on curiosity, so they could imagine the woman they had helped
444 have a baby and the sort of family they had helped create:

445

446 *I just wanted to know what they were like, what they looked like, what they do,*
447 *do they have any other kids? What are they like as people, how long have they*
448 *been trying to have a kid? I wanted their personal statement I guess! That was*
449 *all I needed was their one. It would be nice to know. Just out of curiosity. I don’t*
450 *know where they (eggs) are at the moment. (Claire, 30 years old)*

451

452 Despite their concerns about the implications of identity release and their desire for
453 more information about the recipients and the outcome of their donation, it should be
454 noted that none of the participants had felt the need to take up the counselling they
455 were offered in line with current UK regulations. Rather, the participants believed
456 counselling was only necessary for people who were unsure about becoming donors, a

situation that they did not see as applying to themselves.

Discussion

Although reporting findings from a small-scale exploratory study, this paper has raised some important issues for further consideration in policy and practice, both within the UK, and internationally.

In line with existing literature on egg donors this study has shown motivation to donate to be multifaceted (Purewal and van den Akker, 2009; Kenney and McGowen, 2010; Svanberg et al., 2012). Although the participants described wanting to “help people”, a motivation that in many studies has been classified as ‘altruistic’ (Pennings et al., 2014), this study has uncovered a nuanced view of what “helping” other women means: the participants placed value on their donation due to its ability to give egg recipients the *chance* of having their ‘own child’. This study has also shown the limits of asking about motivation and the value of exploring the meaning of being a gamete donor (Mohr, 2014). It was clear from the participants’ narratives that helping people was something that was mutually beneficial – being a donor made the women feel good about themselves, a finding also noted by Konrad (2005) in her ethnography of egg donation in the UK prior to the removal of anonymity. The rise in compensation for UK egg donors, brought into play by changes in HFEA policy in 2012, does not seem to have affected the current study participants’ decision to donate, with all but one of the egg donors stating that they would have donated “for free”. However, it is clear that the increase in public attention to egg donation that went hand in hand with the change in HFEA policies may have had an effect upon their decision to donate: the majority of the

participants were unaware of egg donation until hearing about the possibility through adverts. With many of the participants stating that most of their family and friends had limited knowledge of egg donation, it seems that awareness campaigns are still necessary.

Due to the arduous, “all consuming” nature of IVF described by infertile women (Franklin, 1997; Becker, 2000; Thompson, 2005), it is perhaps surprising that this study has shown how “easy”, both medically and emotionally, the participants found the processes and procedures involved in donating their eggs. Egg donors describing IVF as quick, easy and relatively painless has also been reported in other studies (Konrad, 2005; Kenney and McGowen, 2010; Almeling, 2011). Konrad concluded that the anonymous UK egg donors she interviewed were “refusing to acknowledge the pain, discomfort and risk” involved in their egg donation. However, Almeling (2011), who noted a similar phenomenon in her study of commercial egg donors in the US, suggested that the reason for utilising a medical technology may affect a person’s embodied experience of that technology. Being paid to undergo hormonal stimulation and egg collection, for example, may cause women to experience this process very differently from women paying thousands of pounds for the procedure in the hope of conceiving a child after years of infertility. Although not receiving the sums of money available to donors in the US, UK donors may still experience the medical and emotional process of hormonal stimulation and egg collection differently due to their motivation to undergo the process: helping others have an ‘own’ child, rather than trying to conceive this ‘own’ child themselves. If concerns regarding the medical and emotional effects of the procedures involved in egg donation were to be allayed by making the actual experiences of egg donors more widely known, perhaps more women would consider donating their eggs.

Problems in juggling appointments, especially not being able to be open with others about donating, were, however, a difficulty the study participants experienced in the process of donation. Increasing awareness and discussion about egg donation would again perhaps alleviate some of this difficulty through enabling egg donors to be open with friends and colleagues about their participation in an egg donation programme. In addition, clinics could run extended hours for egg donors, helping them combine egg donation with work commitments.

The majority of the participants did not complete the pen portrait and goodwill message included as part of the HFEA donor information form, and this paper has highlighted the difficulty that some egg donors experience in providing this non-identifying information. Abdalla et al. (1998) also found that the vast majority (93.5%) of the 585 women who had donated their eggs at a London clinic during a six year period prior to the removal of donor anonymity, did not write a brief personal description about themselves to be passed on to prospective children. In a more recent study, Crawshaw et al. (2012) interviewed twelve key informants (three donor-conceived adults, three egg donors, three sperm donors and three professionals) about the provision of donor information, and conducted a postal survey of HFEA licensed clinics' current practices and factors influencing completion of donor information. All six gamete donors interviewed supported the idea of providing non-identifying information but considered professional assistance to be inadequate, feeling they were not given any structure, prompts, or guidance about the information needs of the child. The findings reported in this paper have shed further light upon the anxieties some donors experience in providing donor information. The egg donors' uncertainty regarding their role and what connection, if any, they have with a child conceived with their donated egg, was central to the difficulty they experienced in writing the pen

532 portrait and goodwill message. For example, if they wrote about themselves as a
533 'person' would this be placing too much importance on their role in the process and
534 would this be painful for a recipient of their egg to read?⁴

535 Interestingly all the donor conceived offspring in Crawshaw et al.'s (2012) study
536 considered information about their donor to be more important than the possibility of a
537 relationship with them. This finding is supported by a growing body of research
538 indicating why donor offspring want information about their donor - for identity
539 formation, satisfaction of curiosity, anxiety about possible genetic inheritance (health or
540 personality) and fears about consanguinity - and what information they would, ideally,
541 like to have about their donor – as much up-to-date social, medical and family history as
542 possible, and a description of what the donor looks like, their personality, temperament
543 and interests (Turner and Coyle, 2000; Scheib et al, 2005; Jadvá et al., 2010; Rodino et
544 al., 2011).

545 Crawshaw et al (2012) concluded that dedicated staff time, alongside written
546 guidance for professionals and donors, is needed to help donors understand the importance of
547 donor information for recipients and donor-conceived offspring, and to help them with their
548 anxiety/reluctance in completing it. The HFEA's National Donation Strategy Group has
549 recently addressed the issue of donor information provision through strategies such as
550 publishing leaflets to help donors think about how to write the pen portrait and goodwill

⁴ The American egg donors Almeling (2011) interviewed also downplayed the significance of their role as an egg donor, maintaining they were donating "just an egg". They also expressed concern for the feelings of egg recipients. However, the US egg donors in Almeling's study provided reams of donor information. At the egg banks at which these US donors were donating, donor information was not just seen as potential information for a donor conceived child: egg donor profiles, with details about the donor's physical characteristics, family health history, educational attainment, as well as open ended questions about hobbies, likes and dislikes, and motivation to donate and photographs of the donor, are used by the egg banks to recruit potential egg recipients. As such, Almeling describes how egg donors are coached regarding the sort of information they should provide and helped to construct gender appropriate profiles.

551 message.⁵ However, results from the current study suggest that the provision of counselling
552 for donors should also be addressed. Although all the egg donors had been offered
553 implications counselling, in line with current HFEA guidelines, none of the study participants
554 had taken up the opportunity of this session. This may, in part, be due to the terminology
555 used to describe the session: they did not feel they needed to be ‘counselled’ regarding their
556 decision to be an egg donor. If a counselling session was advertised as an ‘information
557 session’ the participants may have been more inclined to attend and therefore would have had
558 the opportunity to discuss and explore their thoughts and feelings about being a donor,
559 including the provision of donor information.

560 Alongside difficulty in providing non-identifying information about themselves,
561 the study participants expressed desire for further information about the outcome of
562 their donation. Other studies have also pointed to egg donors’ desire for more
563 information regarding their donation (Fielding, 1998; Klock et al 1998; Kalfoglou and
564 Gittelsohn, 2000; Kalfoglou and Geller 2000; Patrick et al., 2001; Klock et al., 2003;
565 Jordan et al., 2004; Kenney and McGowen, 2010). Of the 20% of US egg donors in
566 Kenney and McGowan’s (2010) study who reported lasting psychological effects that
567 they attributed to having donated, most said this was due to curiosity about the
568 outcome of, and any children resulting from, their egg donation cycle.

569 In known donation, the donor is likely to not only be informed about the
570 outcome of their donation but, in some cases, maintain a relationship with both the
571 recipient of, and the child conceived with, their egg. Yee et al. (2011) reported that
572 Canadian known egg donors whose donation had been successful described their
573 experience as rewarding and life changing, extremely pleased to have helped their
574 recipient realise her parental aspirations. Despite not *knowing* the recipient of their

⁵ The leaflet can be found here: http://www.hfea.gov.uk/docs/Lifecycle_-_Info_for_current_egg_and_sperm_donors_v1.pdf

eggs, the participants in the current study still had an empathy for this imagined recipient. They were donating their eggs to help another woman have an 'own child' and they wanted to know if they had been successful in this pursuit.

Indeed, in the UK donors are faced with somewhat conflicting messages regarding their role as an egg donor. They are anonymous at the time of donation, donating genetic material to an unknown recipient whom they are told nothing about. However, they are also encouraged to see themselves as an important player in a potential child's conception, with their identifying information often framed in terms of a child's 'right' to know their genetic origins (Freeman et al., 2014). Within this context, the current study has shown how egg donors experience uncertainty regarding the identity-release nature of their donation: although donating within a particular legal framework they are unsure what the repercussions of their donation will be. Will the parents disclose their use of donated gametes? Will the child be interested in them as their donor? Will they seek their identity? Will they try to make contact? The egg donors are donating "just an egg" to an unknown recipient yet are signing up to responsibilities through this action: in eighteen years' time they may be faced with the complex situation whereby an individual conceived with their donated egg wants to make contact with them; an individual whom they know very little about, nor the family context in which they have been raised. Indeed, inequality in information exchange was an issue raised in this study: recipients can receive information about their egg donor, in some cases *choosing* a particular donor, but egg donors do not receive any information about the recipient of their egg.

Pennings (1995) has suggested that the removal of donor anonymity increases a donor's involvement and responsibility in the donation process, arguing that being identifiable could reinforce donors' requests to allocate their gametes. Likewise, Raes et

al. (2013) suggested that the shift towards identity-release donation focuses on the rights and interests of donor-conceived children and that 'policy-makers seem to overlook whether information exchange could also be of interest to the other parties involved, in particular the gamete donors. Indeed, the Nuffield Council on Bioethics has highlighted information exchange between donors and donor-conceived offspring as an area requiring further investigation (Nuffield Council on Bioethics, 2013). The findings from the present study suggest that the possibility for donors to receive some non-identifying information about the recipient of their eggs at the time of their donation may make them feel more satisfied and comfortable with their role as an identity-release egg donor.

Conclusions

This qualitative study exploring the motivations, experiences and future expectations of UK identity-release egg donors has shown that the participants' primary motivation for donating was to help infertile women have their 'own child', and the recent increase in financial compensation did not seem to play a significant role. All participants were happy to be identifiable and contacted by children born as a result of their donation. However, some were hesitant about providing non-identifying information about themselves for these offspring and wished for further information about the recipient(s) of their eggs and the outcome of their donation.

Although providing important insights for both policy and practice, the limitations of this study require its findings to be interpreted with caution. This is an in-depth, exploratory study with a small sample size that may not be representative of other UK egg donors. Factors such as age, nationality and ethnicity, and whether a donor has her

own children or not, may all affect the perceptions and experiences of being an identity-release egg donor. When compared with the characteristics of all women registering as egg donors with the HFEA in 2013 (HFEA, 2014), a roughly similar proportion of the study participants had their own children. However, the study participants were younger than the HFEA donors and had a higher proportion of non-British participants, probably because the clinic was based in London. Given the study's small sample size we have not been able to examine sub groups within the sample, for example exploring how an egg donor's age, ethnicity or whether she has children may affect her perceptions and experiences of being an identity-release donor. Larger scale studies are required to investigate these issues further.

Further limitations of the study include a potential selective bias in egg donors taking part, with those willing to be interviewed perhaps having a more positive experience of donation. There is also the possibility of social desirability affecting the narratives of the egg donors, e.g. in terms of financial compensation and motivation to donate. Almeling (2011) found that the US commercial egg donors she interviewed conformed to gendered norms expressed in the clinic where they were expected to be selfless and express empathy for another woman's plight to have children. The current study participants may also be expressing ideals of what they think an egg donor *should* be motivated by, and what it *should* mean to be an identity-release donor.

Further research with both identity-release egg and sperm donors is needed. A research approach that takes gender into account is important in order to enable a discussion of whether egg and sperm donation should be regulated in the same manner (Richards, 2014). Many of the concerns raised regarding identity-release donation, and the provision of donor information, expressed by the egg donors in the current study related to their desire to help another woman have an 'own' child. Almeling (2006,

2011, 2014) found that US egg donors described themselves as ‘not-mothers’ to donor-conceived offspring, whereas sperm donors described themselves as ‘fathers’ to children conceived with their sperm. Gender is thus one factor that may affect a gamete donor’s thoughts and feelings about their role as a donor and their connection, or lack thereof, with the recipient of their gamete(s) and any offspring conceived. Other factors such as age, ethnicity, sexual orientation and whether a donor has their own children or not, may also affect perceptions and experiences of being a gamete donor (see, for example, Daniels et al., 1996; Riggs and Russell, 2010). In-depth, longitudinal studies with both egg and sperm donors need to explore such themes in order to help prepare for the time when donor-conceived offspring are able to request the identity of their donor and possibly make contact with them .

Acknowledgments

We would like to thank the women who took part in this study and the staff at London Women’s Clinic who helped with recruitment. The study was funded by a research grant from the London Women’s Clinic.

Role of authors

All authors were involved in the design of the study. KA assisted with the recruitment of participants. All other authors were involved in the analysis and interpretation of data. This manuscript was drafted by SG and has been approved by all authors.

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