Family building using embryo adoption: relationships and contact arrangements between provider and recipient families - a mixed-methods study

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FAMILY BUILDING USING EMBRYO ADOPTION

ABSTRACT

Study question: What contact arrangements are established between providers and recipients of embryos using Snowflakes® Embryo Adoption Program?

Summary answer: Contact arrangements varied considerably and were generally positively described, although some challenges were acknowledged.

What is known already: Reproductive technologies create new and diverse family forms, and the ways families created by embryo adoption are negotiated in practice have not been extensively investigated.

Study design, size, duration: An exploratory, mixed-methods study with two phases: 1. an online survey (open May-September 2013); 2. qualitative semi-structured interviews by email (conducted between 2014-2015), exploring participants' experiences of contact with their embryo provider or recipient.

Participants/materials, setting, methods: Phase I - seventeen providers (14 women and three men) and 28 recipients (27 women and one man). Phase II - eight providers (five women and three men) and twelve recipients (ten women and two men). All participants except one were located in the US.

Main results and the role of chance: This study illustrates how embryo adoption in the US, as a form of conditional donation, operates and how participants define and negotiate these emerging relationships. All families were open with their children about how they were conceived and early contact between recipients and providers (frequently before birth) was valued. On the whole participants were happy with the amount and type of contact they had, and where the current contact did not involve the children, it was seen as a way of keeping

the channels open for future contact when the children were older. Participants often portrayed the opportunities for contact as in the best interests of the child.

Large scale data: N/A

Limitations, reasons for caution: The study participants are a particular group who had chosen to either receive or give their embryos via an embryo adoption agency in the US and had established contact. Therefore, this is not a representative sample of those who provide or receive embryos for family building.

Wider implications of the findings: The embryo adoption model clearly fulfils a need; some people want to use a conditional embryo donation programme such as Snowflakes®. Some form of 'ongoing support mechanism' such as counselling could be useful for those negotiating the complex sets of new kinship patterns and balancing these with their children's welfare.

INTRODUCTION

This paper examines the results from an exploratory, mixed-methods study of the experiences of people who had both provided and received embryos from Snowflakes® Embryo Adoption Program, part of Nightlight Christian Adoptions in the United States, focussing on the contact arrangements between embryo providers and recipients. One of the defining characteristics of the 'embryo adoption' model is information-exchange and ongoing contact between provider and recipient families, which can be established at the outset.

The study builds on our previous research that explored the experiences of couples who had relinquished embryos through Snowflakes® (Frith et al., 2011; Paul et al., 2010). Several participants referred to contact with their recipient or provider families and the current study was designed to further understand these experiences. The new varied and diverse family forms produced by reproductive technologies are often discussed in the literature (Nordqvist & Smart, 2014), but the specific ways these new families are negotiated in practice has not been extensively investigated. This study throws light on what mechanisms of contact and intra-family relationships this specific group create, contributing to our knowledge of the longer-term psycho-social implications of assisted conception and specifically embryo donation.

BACKGROUND

The first instance of family-building using embryo donation was reported in Australia in 1983 (Trounson et al., 1983). However, in comparison to sperm and oocyte donation, embryo donation remains a comparatively rare form of family-building (de Lacey, 2005; Blyth et al., 2011; Hill & Freeman, 2011). Globally, fewer jurisdictions permit embryo donation than allow sperm or oocyte donation, and considerable legislative, policy and practice

permutations are evident. For example, in jurisdictions where embryo donation is permitted, Belarus, Bulgaria, and Latvia require embryos for donation to be created using separately donated sperm and donated oocytes (Ory et al., 2013), while New Zealand only permits embryos using the donor couples' own gametes to be donated to others for family-building (ACART, 2008).

Embryo "adoption" is a form of conditional donation, where the donor(s) can choose the recipient of their embryo and contact can be facilitated between provider and recipient families (Frith & Blyth, 2013). This offers an alternative to fertility clinic-based anonymous embryo donation programmes, and has been pioneered by private agencies primarily in the US over the past two decades (see Supplementary Material for a more detailed overview of the literature). To date, two research studies of embryo adoption in the US have been reported – both of which involved those using the Snowflakes® programme. Collard & Kashmeri (2011) interviewed 44 provider and recipient parents. The second study (Paul et al., 2010; Frith, et al., 2011) explored the motivations and experiences of 18 couples and seven women who had provided embryos.

MATERIALS AND METHODS

Phase I

An online survey was conducted, open from 21 May - 30 September 2013. Snowflakes® sent an email advertising the study to all eligible individuals: (i) those who had either provided or received embryos via Snowflakes® Embryo Adoption Program; (ii) where at least one child had been born as a result. Snowflakes® had worked with about 800 provider couples and about 500 prospective recipient couples, although not all of the latter would have had a baby, and of these, not all would have established contact with their provider family. At the outset

of the study, it was estimated by Snowflakes® that about 50 pairs of provider and recipient couples might be in some form of contact with each other, although the actual number of such arrangements is unknown. Therefore, we cannot give a precise response rate. It was expected that the majority of participant families would largely contain young children and so the study was restricted to investigating the experiences of adults.

Participants completed an anonymous online survey hosted on Bristol Online Surveys that sought information about: family composition, how many embryos they had either provided or received, the amount and type of contract with their provider/recipient and free responses to comment on how they felt about their experiences. The questionnaire was designed by LF and EB on the basis of their previous research and is available from the authors on request.

Phase II

At the end of the questionnaire, participants were invited to indicate their interest in participating in a follow-up study. In addition to Phase I participants, some new participants were recruited via Snowflakes® and one couple (who had used Snowflakes®) via existing participants. The semi-structured interviews were conducted by EB and LF using asynchronous email. This method was used because participants were based in the US and the researchers in the UK. Interviews took place during 2014 and 2015. Previous experience endorsed the feasibility of this approach to data gathering (Berger, and Paul, 2011; Frith et al., 2011). Analysis of Phase I data formed the basis for the construction of the Phase II topic guide: this covered basic information about the type and frequency of the contact and probes to explore in more depth the participants' experiences of forming these new relationships.

Eligibility for participation in the study included proficiency in English and access to the internet and email. Although these criteria risk disenfranchising potential participants, our previous experience indicated that, in practice, these requirements are met by all couples participating in the Snowflakes® program. Previous researchers investigating fertility issues have experienced difficulty in engaging men; this project was no exception and the majority of participants are women. Both Phases of the study were approved by the University of Huddersfield and the University of Liverpool ethics committees.

Data Analysis

This paper reports data from both phases of the study. Phase I data are analysed using descriptive statistics. Phase I free text responses and Phase II data were analysed thematically to elicit codes in order to identify concepts and the constant comparative method was used to explore the relationship between concepts (Braun and Clarke, 2006). The emergent themes were discussed between team members to explore different interpretations (for more detail on the analytic strategies see Supplementary Material). The source of specific quotations is identified using the following formula: PH1 = phase I; PH2 = phase II; P = provider; R = recipient; F = female; M = male, and their unique number e.g. PH1-PF1, couples have the same number i.e. PH2-PF1 and PM1. Original quotations are reproduced verbatim, except for correction of spelling errors.

RESULTS

Demographics

Phase I

Seventeen providers (14 women and three men) and 28 recipients (27 women and one man) took part in Phase I. Providers reported the birth of 22 children to recipients of their embryos.

Eighteen of these were aged between 0-5 years and four between 6-11 years. Fifteen children were born from embryos created using the gametes of both providers. Four children were born from embryos created using donor eggs. Three children were born from embryos created using both donor eggs and donor sperm (the issue of using donated gametes form embryos is discussed in a further paper from this study, currently under review). Fourteen providers had provided embryos to a single couple; two had provided embryos to two different couples; and one provider had provider embryos to three families.

Phase I recipients had 43 children born as a result of embryo adoption and one recipient was pregnant with her second child (a full genetic sibling of her first child). Of these, 30 were aged between 0-5 years, 12 were between 6-11 years and one between 12-17. There were five pairs of twins. None of the recipients indicated the use of donor gametes in creating the embryos. Nineteen families included only the children resulting from embryo adoption; of these, ten were only children. Three families also included the recipients' "naturally-conceived" children; two families included adopted children, and four families included both "naturally-conceived" and adopted children. Twenty-two recipients had received embryos from one couple only, five had received embryos from two different couples and one had received embryos from three different couples. One recipient family "shared" full genetically-related children with another recipient family.

In Phase II, eight providers (five women and three men) and twelve recipients (ten women and two men) took part (insert Table 1 demographics).

Type and frequency of contact

Snowflakes® offered to mediate contact been families and it was often initiated through Snowflakes:

> *Initially it was facilitated by Nightlight*. (PH2-PM2)

> *We are in touch by email. Initially it was facilitated by Nightlight but recently, we have provided direct email addresses so that we do not need to wait for the message to be delivered by Nightlight.* (PH2-PF2)

However, although this route was often used in the initial stages, most study participants had established direct contact with their respective recipient or provider family. One of the distinctive aspects of the Snowflakes® programme is the ability to arrange contact between each other before the transfer of embryos, and the majority of participants had established some contact before the birth of the child (insert Table 2). The ability to meet before the medical procedures took place was something that our participants valued.

Participants were also asked about the nature and frequency of contact, with contact generally taking place every 2-6 months. Forms of contact mentioned included: exchange of gifts (one provider and five recipients); exchange of videos (two providers and two recipients), exchange of pictures/photo books (four providers and 12 recipients), and use of *Facebook* (five providers and five recipients) (there are additional quotes, material and full data Tables in the Supplementary Material).

In Phase I, eight providers had made face-to-face contact with recipients and seven actively included the children. Nine recipients had made face-to-face contact with the providers of their embryos and six actively included the children (Insert Table 3). Four recipients had met

their provider once, two had met them twice, one had met on three occasions, and two had met once a year since the birth of their child. Of those who had not yet met their provider, two were actively planning to meet, five hoped for future meetings and one indicated they would meet if the child wanted to. Participants frequently reported extensive geographical distances between themselves and their respective provider or recipient family/families and in-person contact, where this had taken place, required considerable logistical preparations and manoeuvres. In some cases contact had included staying in each other's home:

> *…. A few months ago, Family 2 came … to visit and meet us. So the 4 girls and the families all met for the first time. We had sooooo much fun…. We love it! We would love it even more if Family 2 lived closer and we could see them more!* (PH1-PF1,

A recipient who was in contact both with her provider and another recipient of embryos from the same provider recounted how all three families had met up:

> *[Earlier] this year we flew across the country to spend one week visiting our provider family and the other family that is the recipient family of the embryos that are all biological siblings to our daughter….. We had a JOY filled week with our daughter's siblings and family. (PH1-RF6)*

Desire for contact and "open adoption"

The active involvement of both parties in the selection process and Snowflakes® guidance encourage an open approach – i.e. telling the child about their origins and possible contact. The ability to establish some form of contact motivated a significant proportion of study participants to use Snowflakes®.

The attraction to Snowflakes was the opportunity for the open adoption that was not an option through our doctor's office…. We advised Snowflakes that we only wanted to be matched with couples willing to have contact. (PH2-PF1)

The original agreement was to have a semi-open adoption, meaning we would contact as long as it was feasible and we would agree to visits if we were in the same country. (PH2-RF5)

The reasons given for such arrangements included a belief that openness and honesty were in the best interests of the children:

Ultimately, we feel that whatever is in the best interest of our children should come first – regardless is if it's awkward or uncomfortable for us. (PH2-RF4)

Part of this rationale was the desire to facilitate contact between genetic siblings in the different families:

It is extremely important to us that some kind of contact is maintained with the adopting family. We would like our own children to know of their distant siblings, and, if possible, develop a relationship with them. (PH2-PM3)

It is very important that child A and B know their other siblings and have some contact with them. (PH2-RF8)

Further reasons included recipients' desire to be transparent about the process and for their children to have a sense of where they came from:

We want [child] to have a positive sense of identity. We want her to know her story and history (as complete as possible). Understanding her history and where she comes from will help her to understand who she is. (PH2-RF9)

Despite Snowflakes'® endorsement of 'open embryo adoption', this was not mandated for acceptance into its program:

Snowflakes sent us a total of three adoptive family profiles. The first was a couple who was devoutly Catholic and made it clear that they would keep the adoption a secret from their family and even the child. Something just didn't feel right about that. (PH2-PF5)

The genetic family said they wanted a closed adoption…. We decided that it wasn't our first choice, but we went with it. (PH2-RF2)

Views on contact may change over time, and not all participants set out with the intention of having contact, as this recipient shows:

Our original feeling is that we probably wanted as little contact as possible. However, we did put in our profile that we would accept any level of interaction. We were coached that by doing this you would increase the possibility of being selected by a donor family. (PH2-RM3)

However, after initial email contact with the provider family they developed an ongoing relationship:

We are all family now. No other questions or decisions are needed. They are great folks and the girls are sisters which is what is most important to me. (PH2-RM3)

Providers' views also could change; PH2-RF2 reported that her providers initially requested a "closed adoption":

When the twins were born, the agency informed the genetic family ….. About a week later, the genetic mother approached the agency and asked if she could contact us…. The agency asked if we were okay with that (we totally were thrilled!) (PH2-RF2)

Positive aspects of contact

Both providers and recipients thought that contact had to be mutually agreed, with recipients taking the lead in determining how this should develop. For providers, curiosity as to how the child was being brought up, being assured that the child was well cared for and being able to have a relationship with them was an important benefit of contact:

The positives are that we feel satisfied that the twins are being raised in a loving family that adores them. (PH2-PF5)

We were of the mindset that watching the child grow up and being a part of her life was the biggest plus. Being able to LOVE HER!!!! Seeing birthdays, first steps, sports, vacations, etc. We plan to be apart of her life forever. Not knowing leaves too much for the mind to ponder. (PH2-PM1)

The creation of relationships and family bonds was a key positive aspect of contact for both providers and recipients. A recipient mother, who was not initially keen on contact,

developed a very strong relationship with the provider family, who had also given embryos to another family, and all three families had met:

> *We flew with our daughter to meet her sisters and their families. To say the least, it was a truly remarkable visit. This experience and the relationships has be a huge blessing for us in our lives. Not only were we given our daughter, but a whole family too, 2 families actually, or one big family!* (PH2-RF3)

PH2- PF1 also reported developing a close relationship with her recipient family, which started before the birth of the child:

> *Then when she [recipient mother] was around six months pregnant we flew up…to visit them for the weekend. We had dinner and met all of their family then had time just the four of us and I sat next to [recipient mother] with my hand on her belly waiting to feel our bio baby kick. It was an amazing experience. ….We consider ourselves family and share pictures, video's and talk weekly.* (PH2-PF1)

Some participants reported contact with their providers'/recipients' extended family.

> *I am in periodic (quarterly) email communication with the paternal genetic grandfather. We are Facebook (FB) friends and he follows us on FB by liking pictures, status updates, etc.* (PH2-RF8)

> *[M]any family members have befriended our adoptive family on Facebook and follow/comment on their posts, stories, and pictures as well.* (PH2-PF3)

One positive aspect of contact mentioned by both providers and recipients was that it enabled providers to resolve any feelings of wanting the baby back or recipients' fears that their providers might want 'their' baby returned:

> *The only negative thing I can think of at this point was the emotions when she was first born. When I first seen a picture of her and she looked so much like our children I had that feeling of 'that's my baby and I want her'. That feeling only lasted about a week and I think the amount of contact we had helped me get past those feelings.* (PH2-PF1)

> *We were afraid in the beginning of this journey about the family wanting the baby back. And we thought that because they were in [a distant state], we would not be able to see them much and then they would not want the baby. These were all part of our FEARS as we entered into this chapter of our lives.* (PH2-RF3 - who initially did not want contact, has met the providers, and now wishes that the families lived closer to each other)

Negative aspects of contact

Although participants reported overwhelmingly positive experiences regarding contact, some negative experiences were mentioned, particularly regarding concerns about differing parenting styles (see also Supplementary Material):

> *The only negative I can think of is imaginary, at this point at least, and that is a worry over being scrutinized or criticized by the genetic parent.* (PH2-RM5)

One provider gave the following advice:

I think the only thing I would add is that both families have to be aware that this is a very unique situation and they have to be careful not to over-step the boundaries. PH2-PF4

Participants also reported logistical barriers to contact, primarily relating to time and distance. These relationships were characterised by similar problems and issues common to many personal relationships: differing expectations, lack of time to devote to them and geographical distance. As one participant said:

They are too far away for the ability to develop a close relationship with the children at this stage; maintaining the distant relationship takes consistent effort on both families (but I don't think that's any different than any typical family relationship where members are across the country from each other). (PH2-PM3)

Future contact and relationships

One of the main issues facing families when thinking about contact was whether it should include the children or just the adults. Not all the contact between providers and recipients involved the children, the relatively young age of most children in participant families is likely to be a key factor in determining their involvement in contact between families. PH2-RF10 summarised the issues:

We considered these issues separately and therefore we have contact with the genetic parents, but we've chosen to not have our daughter have direct contact with them at this point (other than the visit when she turned two, which she doesn't remember). Some families we know don't have that distinction, so the adopted children have the same or similar levels of contact as the adoptive parents do. It's just interesting to

note different families' opinions and perspectives on contact, and how they view it as impacting the children's emotional health (or not).

For her, contact was restricted to the adults and:

we don't expect any changes in contact, except for when our daughter gets into her teen years and if she requests to have contact herself - we will have to pray and discuss when is the right time and way for that to happen.

For a number of participants contact was established to enable their children, when older, to be able to make contact themselves:

We have never met either family face to face. We don't know if we will ever meet them face to face. We will meet them if the kids decide that they are at a place that they want to meet their genetic family. At what point they will decide to do this, we have no idea…. Right now our main goal is to have the same level and type of contact with each family until each of our children come to that cross road. (PH2-RF7)

[Daughter] will probably opt to have some contact with them [providers] or meet them, which is fine, after she is 18. She can make her own decisions then on developing a relationship with them and set the boundaries herself. It takes the pressure off of us as parents to do that now. (PH2-RF1)

DISCUSSION

To our knowledge this is the first study to explore how embryo adoption in the US, as a form of conditional donation, operates and how participant families define and negotiate the relationships created. The contact arrangements varied considerably – but all created the opportunity for future contact to be initiated by the child(ren) when they were older (if they wanted to). Generally the contact was positively described, although some challenges were acknowledged.

Conditional embryo donation programmes are rare, New Zealand is one of the few jurisdictions outside the US that operates such a programme and thus studies conducted in New Zealand most closely mirror our study population (for an overview of studies on embryo donation see supplementary material). Goedeke et al. investigated the views and experiences of participants (thirteen potential recipients of donor embryos (Goedeke & Payne, 2009) and 22 embryo donors and 15 recipients (Goedeke et al., 2015). These studies highlighted the significance of genetic connections and relationships, "both donors and recipients regarded genealogy and genetic knowledge as critical for well-being and identity, and as bestowing immutable kinship ties between donors and offspring." (p. 2345) They argue that this resulted in providers being concerned about who received their embryo and feeling some 'moral responsibility' for the child's future well-being. As has been noted both by our participants and in other literature (Taylor, 2005), embryo adoption/donation is a unique way of forming a family and Goedeke et al. (2015) found that the metaphor of embryo donation as adoption was used by their respondents to make sense of this 'unique' process. Their respondents, like ours, conceptualised the process of embryo donation as creating an extended family and talked about the creation of new, complex kinship relationships that managed, "the interplay

between genetic, gestational and social aspects of reproduction and family building." (p. 2340).

The temporal nature of decisions was a key theme in our data. We found that some couples did not start out in favour of openness or contact, and their attitudes changed over time. Often, once the child was born, they found that they wanted to be open and form a relationship with the provider/recipient family. Relationships could also change, with some developing into deep friendships and others withering. Therefore, intentions as to how much contact and what type might be desirable were not always realized in practice. A key element of the importance of openness and contact for some participants, was to give the child the option when they were 'old enough' to make their own decision regarding contact with their provider family. As Kirkman (2004) has noted, family dynamics change and the temporal nature of intentions and experiences of forming a family through embryo adoption are often not captured. While our study presents only a view from a 'slice' of time in these families' lives, our results point to the importance of considering the life-course implications of forming families in this way. Families live with these decisions and resulting relationships for the rest of their lives and there is a need for further studies that consider these experiences in the longer term.

Both embryo recipients and providers were clear that the welfare of any children produced from embryo adoption and of any other children in the respective families should be a central consideration. There was also a recognition by both groups that the recipients were 'the' parents and 'had the right' to make the parental decisions, without interference or judgement from the providers. Both providers and recipients mentioned aspects of the inherent tensions in this position, but the repertoire of traditional infant adoption was employed to give

legitimacy to locating the recipients as the parents. Overall, our participants were generally happy with the relationships they were developing with their opposite number. The difficulties were seen as not dissimilar to other forms of relationships, when it was hard to maintain regular contact and thus the relationship suffered. The most common negative issues arising were lack of contact either due to time pressures, geographical distance or a miss-match in expectations.

Study Limitations

This study focussed on those who had chosen to either receive or given their embryos to others via an embryo adoption agency and, of that group, those who wished for and had established contact. Therefore, it does not capture those who did not want contact or their reasons for this. Hence, the study's results cannot be extrapolated to other populations who provide or receive embryos for family building. The location and political context of embryo adoption in the US is a distinctive one and Snowflakes®, as a Christian adoption agency, obviously defines the likely clientele and limits the wider applicability of our findings. However, the studies carried out in New Zealand did highlight some common issues, hence our findings reiterate some of the themes found in other studies. The qualitative research was conducted by email, and arguably there are some limitations to this method: the researcher cannot pick up on visual and voice responses, build a rapport or clarify responses. However, there are also positive benefits of using this method. At the end of the interview we asked participants how they had found the email interview process, and some reported that it had enabled them take their time to think about their experiences and reflect on their answers – something that may not be so readily facilitated in conventional face-to-face interviews.

Implications for practice

The embryo adoption model clearly fulfils a need; some people want to provide and receive embryos under such a conditional programme. How popular such a programme would be in other contexts is unknown, however as openness as an approach to gamete and embryo donation grows so might such programmes (Blyth & Frith, 2015). These technologies build families, going well beyond a medical intervention located in the clinic – they have long term repercussions. In recognising this, given the unique challenges facing both recipients and providers of embryos, Goedeke et al., (2015) recommend some form of 'ongoing support mechanism' such as counselling might be useful for those negotiating the complex sets of new kinship patterns and balancing this with their children's welfare. There is, however, a lack of ongoing support for those involved and the children produced from reproductive technologies. As found in other studies (see Crawshaw et al., 2016) specialist support is needed – people trained in the distinctive issues that might arise from these forms of family building – and providing this is a challenge that has still not been adequately addressed.

CONCLUSION

The use of embryos provided by a third party for family building is a contested form of reproductive technology. A conditional programme of embryo donation, such as that that operates in New Zealand and of which Snowflakes® is an example, are even more contentious and couching embryo donation as adoption has caused some controversy (ASRM, 2016). However, conditional or embryo adoption programmes could provide an alternative to an anonymous, clinic based model and give those who have surplus embryos the opportunity to choose who they wish to donate to and if they wish to have and maintain contact in the longer term.

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AUTHORS' ROLES

LF and EB designed the study and collected the data. All three authors analysed and interpreted the data, drafted and revised the manuscript

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