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We wanted to choose us: how embryo donors choose recipients for their surplus embryos

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ABSTRACT

Objective: This study aimed to explore factors affecting donors' choice of recipients for their surplus embryos in the New Zealand context of conditional, known donations.

Background: Internationally, embryo donation has a low uptake in spite of large numbers of cryopreserved embryos. Possible reasons include a lack of knowledge about and concern for the future welfare of the resultant offspring. In New Zealand, donors and recipients meet prior to donation and legislation supports disclosure and access to genetic knowledge.

Method: Twenty-two embryo donors (10 couples, two individuals) were interviewed between March 2012 and February 2013 about their experiences of donation and factors affecting their donation. Interview data were analysed thematically.

Results: In the interests of the welfare of the child resulting from donation, donors were invested in choosing recipients who would make suitable parents. They attempted to choose recipients similar to themselves, as well as those that they trusted to disclose the manner of conception and facilitate agreed-upon information exchange and contact.

Conclusion: The interest of donors in ensuring offspring well-being may lend support to conditional forms of open donation, allowing for assessment of recipients' suitability to parent, and for negotiation around information exchange and contact.

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Embryo donation; donors; parenting suitability; disclosure; information exchange

Introduction

Embryo donation refers to the donation of embryos remaining after in vitro fertilisation (IVF) to others confronting infertility. New Zealand's policy and practice with regards to embryo donation are aligned with trends towards open identity donation as evident in the United Kingdom, Australia, Canada, Sweden, Norway and the Netherlands (Garcia-Ruiz & Guerra-Diaz, 2012; Hammarberg, Johnson, & Petrillo, 2011). It is, however, the only country in the world in which policy requires that donors and recipients meet *prior* to the donation. According to the guidelines set by the government-appointed Advisory Committee on

Assisted Reproductive Technologies (ACART, 2008), embryo donation requires first individual counselling of donors and recipients, in which motivations for, feelings about and expectations of donation; grief and loss around genetic connection; and the needs and rights of children are explored. Counsellors will record information as to donors' wishes around recipient characteristics and families, and assist recipients to draft profiles from which donors will select those recipients they would like to meet face-to-face in joint counselling. In the joint counselling session donors and recipients get to know each other and explore expectations of information exchange and contact, before an application is made to by the clinic to ECART (Ethics Committee for Assisted Reproductive Technologies – another government-approved committee). While donors and recipients may thus be 'choosing' each other for embryo donation, the first point of choice, unlike conventional donation practice where gamete recipients select their donors, rests with the prospective donors.

Embryo donation has been available in New Zealand since late 2005 only, and in spite of the large numbers of cryopreserved embryos and anticipated interest from recipients, uptake has been low. In the period 2006–2013, 54 applications were made to ECART, all of which were ultimately approved. In-depth individual counselling helps to ensure that prospective donors and recipients have thoroughly explored relevant issues before they are shown each other's profiles, and joint counselling sessions address issues on which ECART requires agreement, such as expectations around disclosure and contact. Such factors are important to clarify, because while embryo donation guidelines draw on legislative principles (the Human Assisted Reproductive Technology Act [HART], 2004) which include that offspring should be made aware of their genetic origins and be able to access information about those origins, disclosure itself is not mandated and, ultimately, the decision to disclose rests with the recipients.

Donors do not usually have a large range of choice of prospective recipients, typically being shown one to three profiles. While the number of applications has increased somewhat since more embryos have reached or are approaching the mandated 10-year storage deadline in New Zealand (ACART, 2008) the numbers remain low – a review of the most recent ACART report (2016) indicates 13 applications for the period July 2014–June 2015.

Factors that have been cited in international research that may influence donation decisions are reported to include donors' ongoing concerns about the offspring's well-being and a sense of ongoing emotional ties (Blyth, Frith, Paul, & Berger, 2011; Richards, Pennings, & Appleby, 2012). Some researchers have suggested that 'some families are so worried about putting their embryos in the wrong family' that they do not donate (de Lacey, Rogers, & Richards, 2010; McMahon & Saunders, 2007). Directed conditional donation, where donors may specify desired characteristics of the recipients, such as the recipients' age, marital status, ethnicity, socioeconomic class or sexual orientation, has been argued to lead to a greater comfort around donating (Frith & Blyth, 2013; Frith, Blyth, Paul, & Berger, 2011; de Lacey et al., 2010). So too has the ability to donate under open-identity conditions (Frith et al., 2011; Fuscaldo, Russell, & Gillam, 2007), particularly in lieu of some research linking knowledge of genetic heritage to healthy identity development (Allan, 2010; Blyth, 2012; Daniels, Grace, & Gillett, 2011). Embryo donation in New Zealand is both a form of conditional donation and an extension of it, as donors may not only specify characteristics they desire, but meet and actively select recipients. It is thus also open-identity.

The research reported here was part of a wider research study exploring how donors and recipients in New Zealand understood and experienced embryo donation policy and

practice, and was the first study of embryo donation in this country (see Goedeke, 2014; Goedeke, Daniels, & Thorpe, 2016; Goedeke, Daniels, Thorpe, & Du Preez, 2015). Findings from this wider study suggest that both donors and recipients regarded the genetic connection between donors and recipients as significant and as bestowing ongoing social ties, and that they framed embryo donation as building new and extended kinship forms. In this paper we report findings from the study related to how donors choose recipients against a backdrop of being able to not only specify desired recipient characteristics and donate under open-identity conditions, but being able to meet the recipients with whom they could, at least in theory, have varying degrees on ongoing contact from the outset.

Method

Recruitment for this study occurred between March 2012 and February 2013. Fertility clinics in New Zealand are responsible for embryo donation applications to ECART and must keep records of all applications and their outcomes. Clinic staff sent information about the study to all 54 eligible donor couples on their database. The information included a Participant Information Sheet as well as a letter from the clinic inviting those interested in participating to make direct contact with the researcher, thus ensuring that the clinic would have no access to the identity of study participants. Those interested in participating were given the choice of being interviewed as couples, or as individuals.

Data collection was via the means of semi-structured interviews which included questions related to general topic areas such as participants' experience of infertility, the ways in which they perceived embryos, and their experiences of donation practice and policy requirements. Of particular relevance for this paper, questions within these topic areas also related to factors influencing decisions to donate and their choice of recipients. While these indicative questions guided the interview format, opportunity was also provided for participants to raise or elaborate on issues significant to them. Demographic data related to common variables such as age, socioeconomic group, marital status and educational level as well variables particularly relevant to the topic area such as number of children, number of treatment attempts and number of embryos in storage were collected either at the outset or conclusion of the interview. Participants signed consent forms prior to the interviews.

Interviews were transcribed verbatim and pseudonyms were used and identifying information was disguised. Participants were given the opportunity to amend their transcripts as desired. In accordance with ethics requirements, data and consent forms remain stored in hard copy and electronically for a period of 6 years, after which they will be destroyed.

Data were analysed thematically using Braun and Clarke's (2006) well-established six-step process of interpretive thematic analysis, including: data familiarisation through the reading and re-reading of each transcript while taking note of patterns in the data; generating initial codes by identifying meaningful groups of data and highlighting relevant data extracts; sorting codes into broader categories through identifying commonalities and differences; reflecting and redefining themes in discussion with the study's co-author and supervisors and with reference to excerpts; and considering their coherence and inter-relationships (Braun & Clarke, 2006; Willig, 2013). As suggested by Willig (2013), a clear audit trail outlining the process followed was kept to ensure rigour.

Ethical approval for this study was granted by the Ministry of Health Regional Ethics Committee (dated: February 2012, Number CEN/11/12/07/071AM02).

Results

Of the eligible population of 54 donor couples, 22 people (10 couples and two individuals) responded and agreed to participate. Six donor couples (12 people) had 'successfully' donated, i.e. their embryo donation had resulted in births (seven children). Donors varied in age from the early thirties to the mid-fifties, and were represented by a range of educational levels and socioeconomic backgrounds. Twenty donors were European and two were Asian. No Māori were recruited for this study. While participants were recruited through the main clinics in New Zealand (with centres in Auckland, Hamilton, Wellington and Christchurch), interviews took place throughout New Zealand. Participants came from clinics providing both public and private services.

With reference to factors affecting donors' choice of recipients, three main themes were identified: that recipients should be similar to themselves or people with whom they felt they could build good relationships; that certain characteristics were important to ensure a 'good' upbringing for the child; and that recipients needed to be committed to disclosure and open to information exchange. Themes are presented below along with excerpts that appropriately exemplify each theme.

Recipients should be good parents: 'people like us', or 'people that fit with us'

For donors, the welfare of the child potentially resulting from embryo donation was a significant factor guiding their decision-making, and thus they wanted recipients that would make 'good' parents. It was interesting that donors located themselves as responsible for choosing the 'right' recipients to ensure the child's well-being:

You want to make sure you are giving that child the best you can, because you don't want to put that child into a position of having a horrible life because *you* made a bad choice. (Grace)

The 'right' recipients were seen to be either those who were most similar to themselves in outlook or characteristics, or with whom they could identify and form sound relationships. In an attempt to achieve a match, donors thus looked for 'the same sort of upbringings' (Janet), recipients who 'were the most like us' (Roy), or who had 'similar kind of philosophies to you, and feelings on life' (Stephen). As genetic parents to the offspring, they regarded themselves as best-suited to being the parents of the child resulting from embryo donation. Brian believed that characteristics were genetically inherited, and expressed uncertainty about whether parents who didn't share those genetic characteristics would know how to manage characteristics unfamiliar to them. He commented:

Y is our flesh and blood, and so we can understand all that. They (recipients) won't. What are they going to do?

By aiming for a close match, donors felt more assured that the recipients would be able to manage such issues and be people 'who (are) going to raise your children in a way you would want them raised' (Grace). The desire for a match was also to avoid future negative comparisons:

We didn't want a big disparity and that my children look and say, 'Oh I wish I had gone to that family, and why can't I go off there and have what they've got?' or vice versa. (Janet)

Secondly, relating well, or having a 'connection' that felt 'right' (Jack) was similarly valued. Janet, for example, said:

They are people, as soon as I met them, that ... if I had met them in different circumstances, I could have a relationship with.

This was framed as providing the basis for future sound relationships, which were regarded as in the best interests of the child, especially given that in the New Zealand context, contact could possibly continue and that the chances were high that offspring would or could meet.

Desired characteristics: in the interests of the child's welfare

Most donors had ideas around characteristics they wanted the recipients to have. These were again framed with reference to the welfare of the child. For example, donors valued financial security, with Lance explaining:

It was never really about the money side of things for us; it was really more about the fact that so long as it wasn't going to be a poverty situation ... knowing that the child would be well looked after ... we didn't want someone that was going to live on the bones of their arse.

Having family support that recipients could rely on to raise their child was also constructed as important. Donating to a single parent was not necessarily seen as problematic, as long as there were adequate support structures. Isla spoke of her recipient, who was single, as having a 'very good family network, a very supportive family' and expressed that 'to us that was important'. Where donation was to a couple, relationship stability was framed as significant for the child's optimal welfare. Mandy explained:

We really wanted that they were in a committed relationship. We didn't want the baby to be in the middle of a custody battle. It was a funny thing, you don't normally say to another couple, 'You have to stay together!' We didn't say it like that, but the message was, and it was obviously framed nicely, 'It's really, really important to us that these embryos go to a couple that are really committed and really stable'.

Recipients with previous experience with children, particularly with those different from the mainstream in some way, were valued. This led to donors believing that recipients were 'used to that side of things' (Kimberley) or 'had dealt with those sorts of issues' (Jack).

Health and age were also important, insofar as donors assumed that good health was needed to raise a child, because 'it's going to take energy to raise young children' and that ideally 'our parents (recipients) need to be around longer for them, for important things in life' (Jessica).

Achieving a match of characteristics between donors and recipients was again seen as relevant. In this regard, sexual orientation was constructed as important, with Stephen drawing on a genetic discourse with his comment that:

I was more upset about the same sex side of things, because I thought for someone who was of my genetic makeup, that's not us. We come from a heterosexual background, so I preferred a heterosexual background.

Likewise, for those donors with a strong religious affiliation, donating to couples with similar beliefs was important. Jack mentioned, 'That was part of that process, with one of (the criteria) being that we would like to see the embryos go to a Christian home'.

While there were some variations in the characteristics donors desired in their recipients, overall donors were looking for two things: first, characteristics that they felt would contribute to the recipients making 'good' parents who would ensure the child's optimal welfare. Second, characteristics that would achieve a match with their own family were valued and regarded as contributing to the child's well-being.

Recipients prepared to disclose and open to information exchange

Donors in this study were clear that they wanted recipients that would tell the child about his or her origins, and allow the possibility of contact. This stemmed from a belief that information and access to genetic heritage were in the child's best interests. Grace explained:

It's what's the best interest for (the child). We've said to them, 'It's not about what we want, or really what *you* want, it's about what's best for B.' Because I said there may be times when we are wanting to see B more for us, but you may say, 'Look it's not a good time; just back off.' And that's OK. Or there may be times when you say to us, 'We need you to come and spend some time with B'; and it may be a bad time for us, but we will come and do it for B, because it's not about us, it's about B.

Donors did not necessarily, however, seek face-to-face contact. Jonathan said:

I'm pleased that they live that far away, because if they were just 5 minutes down the road and you had an awful lot more contact, it could be a lot more difficult for me.

Contact also did not need to be frequent contact, since, as Roy stated, they wanted 'to be part of their lives *from a distance*'. Some were willing to play a more direct or supportive role, as expressed by both Lance, who indicated that they would be willing to care for the child should anything happen to the recipients, and Grace, who offered support to the recipient woman during pregnancy. She explained how:

When (our recipient) had the pregnancy (difficulties) nobody knew. I was like, 'you need support'. So, a friend and I came up ...

Regardless of the type of contact desired, all donors were aware of the need for the donor-conceived child to form an attachment with the recipients. They thus left the degree of contact to the recipients. Nathan explained:

We are leaving the door open for them to keep updating us, because we don't want to encroach and make them uncomfortable or uneasy. It's their universe, and when they are ready, they will develop that openness a bit more.

It was interesting that meeting the recipients was considered to be important to assess recipients' match with their family, their characteristics and their willingness for disclosure and openness. Otto described the joint meeting as 'crucial'; and several donors spoke about the importance of this meeting to make what they regarded as an 'informed decision'. Indeed, the majority of donors expressed a desire to have extended opportunities to get to know each other, with some speaking of having circumvented clinic policy to have contact outside of the joint meeting. All donors in this study regarded embryo donation as having long-term implications or as being a 'lifelong decision' (Grace), regarding the recipients and their family as 'people that you are potentially going to have a relationship with for the rest of your life' (Jack).

However, several donors also spoke about the limits of the selection process and joint meeting, and their frustration at being unable to ensure good parenting, disclosure and information exchange. Brian for example, expressed concern that no home study was done. Grace spoke of her awareness that information exchange arrangements might not be honoured, saying:

If they change their minds, there's nothing we can do about it. We knew that from day 1: this is a risk; that they could get the babies they want, and then they can say, 'See you later'.

Finally, donors had to accept that the donation was made knowing that they had done all they could to select recipients that would make suitable parents and would disclose. As Lance commented:

The long and the short of it is, once we made that decision for it to happen, the majority of those things are out of your hands anyway. In good faith you say, 'You bring that child up in your best possible way' and we will be there to help support if you require anything, but it's your child. It's out of our hands. We are never going to have any say ... and we always knew that. But you make that decision; you pick the people you are happy with, their basic personality, how they are and their beliefs and whether they are caring, giving people, because that's it.

Discussion

Results from this study suggest that donors thought beyond the act of donating to what the embryos would become if the donation was 'successful' – children, for whose welfare they assumed responsibility. This may stem partly from a sense of having helped bring these children into the world, as is also indicated in other research (Crawshaw, Gunter, Tidy, & Atherton, 2013; Daniels, Kramer, & Perez-y-Perez, 2012; Goedeke et al., 2015; Jadv, Freeman, Kramer, & Golombok, 2011; Riggs & Scholz, 2011). It may also be related to donors' sense that through their genetic ties, they were still connected to, and thus responsible for, the offspring in some way (Goedeke et al., 2015, 2016). Indeed, some research suggests that donors continue to see themselves as having a degree of parental responsibility for offspring resulting from donation (Crawshaw et al., 2013; Goedeke et al., 2015; Paul, Berger, Blyth, & Frith, 2010). Similarly, in our study, donors made decisions with reference to the welfare of the future children resulting from embryo donation.

Such a sense of responsibility for the child's welfare offers an explanation for donors' wishes to be involved in the selection of prospective recipients and for there being an assessment process. Our study's findings in this regard lend weight to the studies of Fuscaldo et al. (2007) and McMahon and Saunders (2007) which suggest that an extension of typical conditional donation, going beyond the ability to impose conditions on recipients to an active process of selection (as is the case in New Zealand) or assessment, may be useful and may increase the likelihood of willingness to donate. Wanggren, Prag, and Skoog Svanberg (2013), for example, found that most Swedish couples with surplus embryos supported embryo donation, but particularly when they were able to specify restrictions on recipient characteristics. Having an active role in choosing recipients helped donors in one study feel as if they were ensuring an adequate home for the children (Frith et al., 2011).

While donation practices have typically focused on donor eligibility, the American Society for Reproductive Medicine's (ASRM, 2013) guidelines include 'assessment' of recipients, although their emphasis is seemingly on the recipients' ability to cope with the stressors of treatment. In New Zealand, policy guidelines specify police checks and a review of minutes suggest an interest by the ethics committee in donor: recipient family match (in terms of background) and the psychosocial history of recipients, both of which suggest a degree of assessment (Goedeke & Daniels, 2017). The New Zealand Law Commission's (2005) recommendation to enact a need for more formal parenting assessments was, however, rejected by government.

In our study, donors were interested not just in ensuring characteristics that they regarded as making for good parenting, but also in recipient families that 'matched' with their own. In research of other 'open' embryo donation arrangements, such as in Paul et al.'s (2010) study, finding the 'right match' with the donors' family, often a family that resembled their family in values and experiences, was similarly important for donors. Likewise, Collard and

Kashmeri (2011) describe how donors were looking for families comparable to themselves in spirituality, marriage and family values, education, income and race. In our study, achieving a close match was again constructed with reference to the best interests of the child, both in having a parent capable of understanding and managing the child's genetically pre-determined characteristics, as well as minimising any negative comparisons between the families which might occur in 'open' systems where contact is possible.

The active selection of recipients and meeting between donors and recipients share some parallels with adoption practice. Indeed, some programmes such as the Snowflakes programme in California, and the Beginning Family Services programme in Canada, promote embryo donation as early adoption and mirror their practices on those of adoption, screening and conducting home studies of recipients and facilitating meetings between donors and recipients (Blyth et al., 2011). While other jurisdictions may not explicitly frame embryo donation as adoption and stop short of formal parenting assessments, they too may be assuming practices drawing on those of adoption such as attempts at matching and selection of families (de Lacey et al., 2010) and child protection order checks (Hammarberg et al., 2011). These are similarly argued to be justified through an emphasis on 'the best interests of the child' (de Lacey, 2007).

In this study, donors' choices were also influenced by recipients' willingness to engage with an open identity system. Conditional models, especially those which allow for active selection and meeting of donors and recipients, may be more likely to promote openness (Goedeke, 2014). With some notable, contested exceptions (see Pennings, 2017 and the response from Crawshaw et al. 2017), disclosure and access to information about genetic heritage have often been highlighted as significant for the well-being of offspring, both in research on donor conception as well as adoption (Appleby, Blake, & Freeman, 2012; Blyth, 2012; Daniels, 2004; Daniels et al., 2011; Karnein, 2012; Palacios & Brodzinsky, 2010; Richards et al., 2012).

Yet while the welfare of the child appears to guide donors' decisions in this study, and is given weight by researchers and policy makers internationally, whether or not selection and assessment, or meetings between the various parties, facilitate the welfare of the child are open to debate. For example, social criteria may not necessarily make for better parenting (de Lacey et al., 2010), conditional donation may not guarantee a child good parenting and assessments may be subjective (Allan, 2010; Goedeke et al., 2015; de Lacey, Peterson, & McMillan, 2015; Thorpe, Croy, Petersen, & Pitts, 2012). Even in adoption research, there is debate around the nature of eligibility and suitability requirements and the role of birth parents in placement decisions (O'Halloran, 2015). Furthermore, as donors in this study pointed out, while disclosure and openness may be regarded as in the best interests of the child, even in open systems such as the one in New Zealand, the decision to disclose still rests with the recipients as the birth certificate records the information of the recipients (or adoptive parents) only (Gibbs & Scherman, 2013). While birth certificate annotation has been suggested (New Zealand Ministry of Justice, 2006) and ACART has recently released a consultation document that seeks feedback on 'potential strategies to strengthen offspring access to information about their origins' (Advisory Committee on Assisted Reproductive Technology [ACART], 2017, p. 21), the situation in New Zealand remains unchanged and the debate around birth certificates continues in both the realm of donor conception and adoption (Allan, 2010). As de Lacey et al. (2015) point out, how the child welfare principle may be applied in practice remains unclear. Finally, it is also important to acknowledge that while

there is clearly a child whose interests need to be paramount in the case of adoption, in embryo donation there is 'not yet' (or even, may not be) a child whose interests need to be recognised (ASRM, 2016; de Lacey et al., 2010, 2015). Promoting the needs of potential children and restricting access of prospective donors on the basis of their characteristics may also be considered discriminatory (de Lacey et al., 2015). Furthermore, research into open, conditional embryo donation is in its infancy, and it is too soon for conclusions to be drawn about the outcomes for offspring and factors related to positive outcomes (Frith & Blyth, 2013). Only a handful of studies have explored the development of families formed through embryo donation (e.g. Frith et al., 2011; Frith, Blyth, & Lui, 2017; MacCallum, Golombok, & Brinsden, 2007; MacCallum & Keeley, 2008, 2012; Paul et al., 2010). In the studies conducted by MacCallum and colleagues, children in early and middle childhood were reported to be doing well, in spite of a context of anonymity and most parents reporting that they had not or were not planning to disclose to their children. As the authors acknowledge, however, the longer-term implications of these forms of embryo donation may yet be uncertain. Frith et al.'s (2017) study, which explored relationships and contact arrangements between families who had donated embryos or built their families through the Snowflakes embryo adoption programme, found that while families were open with their children about how they were conceived and valued early contact, initial intentions as to the nature and frequency of contact were not always realised in practice. It is thus also important to recognise that factors that may be important to donors in their decision-making around donation, including openness and contact, may not always be guaranteed and are open to change.

Nonetheless, Blyth et al. (2011) suggest that current research does not support a compelling case for the pre-eminence of any single model for embryo relinquishment. Frith and Blyth (2013) suggest that a range of models, including those that allow for screening, be available, arguing that these allow donors to exercise their reproductive rights and that there is no evidence to suggest that these models would be harmful. Frith et al. (2017) go on to argue that an embryo 'adoption' model clearly fulfils a need and that some people wish to provide or receive embryos under such conditional models. While our study was based on a small sample, representing 22% of eligible participants in New Zealand, and while 20 of the donors who participated did so as couples and might thus share similar views, our study suggests that at least for a proportion of donors, their willingness to donate may be affected by enabling donation under certain conditions, such as the selection and assessment of recipients, and requiring open-identity practices. It is thus important to consider how donors experience such conditions, as we have attempted in this study, and to conduct future follow-up studies to assess the longer-term implications.

Conclusion

Our study suggests that the welfare of the child resulting from embryo donation is an important factor influencing donors' choice of recipients. Donors may wish to be involved in the selection of recipients in an attempt to ensure that the recipients will make suitable parents, and that the child will have access to knowledge about his or her genetic heritage. New Zealand's conditional, open model of donation accommodates these needs of donors to some extent, but is not without its difficulties. First, there are limits to donors' ability to make decisions around suitability for parenting, there is no formal screening of recipients and active selection does not guarantee successful outcomes. Second, although the model

advocated is open, the decision to disclose the means of conception, to share information, or to have contact, rests with the recipients. Nonetheless, the interest of donors in trying to ensure offspring well-being expressed in both this and other international studies lends support to the consideration of conditional forms of open donation.

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