

Embryo donation and understanding of kinship: the impact of law and policy

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STUDY QUESTION: What is the impact of law and policy upon the experience of embryo donation for reproductive use?

SUMMARY ANSWER: Access to, and experience of, embryo donation are influenced by a number of external factors including laws that impose embryo storage limits, those that frame counselling and approval requirements and allow for, or mandate, donor identity disclosure.

WHAT IS KNOWN ALREADY: To date only three qualitative studies in Australia and New Zealand have been completed on the experience of embryo donation for reproductive purposes, each with a small cohort of interviewees and divergent findings.

STUDY DESIGN, SIZE, DURATION: Embryo donors, recipients, and would-be donors were interviewed between July 2010 and July 2012, with three additional interviews between September 2015 and September 2016, on their experiences of embryo donation. The sampling protocol had the advantage of addressing donation practices across multiple clinical sites under distinct legal frameworks.

PARTICIPANTS/MATERIALS, SETTINGS, METHODS: Participants were recruited from five Australian jurisdictions and across 11 clinical sites. Twenty-six participants were interviewed, comprising: 11 people who had donated embryos for the reproductive use of others (nine individuals and one couple), six recipients of donated embryos (four individuals and one couple) and nine individuals who had attempted to donate, or had a strong desire to donate, but had been prevented from doing so. In total, participants reported on 15 completed donation experiences; of which nine had resulted in offspring to the knowledge of the donor.

MAIN RESULTS AND THE ROLE OF CHANCE: Donors positively desired donation and did not find the decision difficult. Neither donors nor recipients saw the donation process as akin to adoption. The process and practice of donation varied considerably across different jurisdictions and clinical sites.

LIMITATIONS, REASONS FOR CAUTION: Because the pool of donors and recipients is small, caution must be exercised over drawing general conclusions. Saturation was not reached on themes of counselling models and future contact.

WIDER IMPLICATIONS OF THE FINDINGS: The differences between our findings and those of a previous study are attributable to varied legal and counselling regimes. Therefore, law and policy governing embryo storage limits, counselling protocols and identity disclosure shape the donation experience and how it is described.

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Introduction

Much of the available research into embryo donation for reproductive use considers general IVF patient attitudes; exploring why patients do not donate (Kingsberg *et al.*, 2000; Newton *et al.*, 2003; Bangsbo

et al., 2004; de Lacey 2005; Lyerly *et al.*, 2006, 2010; Fuscaldo *et al.*, 2007; Newton *et al.*, 2007; McMahon and Saunders, 2009; Melamed *et al.*, 2009; Mohler-Kuo *et al.*, 2009; Nachtigall *et al.*, 2009; Takahashi *et al.*, 2012; Wanggren *et al.*, 2013).

In Australia, as elsewhere, embryo donation for the reproductive use of others is uncommon, with only around 10–15% of unused embryos donated to others (Kovacs et al., 2003; Hammarberg and Tinney, 2006). The experiences of those who are embryo donors and recipients are rare; only three qualitative studies exist across Australia and New Zealand (de Lacey, 2007a; Millbank et al., 2013a; Goedeke et al., 2009, 2015), each drawing upon a small pool of interviewees. The de Lacey study interviewed 15 people (seven women and four couples) who donated embryos (de Lacey, 2007a). The Goedeke study interviewed 37 people: 22 embryo donors (10 couples, 2 individuals) and 15 recipients (five couples, five individuals) (Goedeke et al., 2015). Our study interviewed 26 people: 11 participants who donated embryos (one couple and nine individuals), six recipients of donated embryos (one couple and four individuals) and another nine individuals who had attempted to donate, or had a strong desire to donate, but had been prevented from doing so.

The most recent study by Goedeke in New Zealand reported that ‘the genetic link between the donors and donor-conceived offspring was regarded by both donor and recipients as bestowing immutable social connections’ (Goedeke et al., 2015) and found that both donors and recipients used an adoption metaphor to describe the longer term implications of having a genetic child separated from and raised by another family (Goedeke et al., 2015). This finding stands in direct contrast to the authors’ findings, and those of de Lacey, that participants did not understand the experience of embryo donation as akin to adoption, in particular that any offspring was not relinquished but was rather born to the recipient mother.

Significantly, these studies draw interviewees from different legal and policy regimes. In particular, rules governing embryo storage, donor and recipient counselling and identity disclosure varied across the studies. The Goedeke study (Goedeke et al., 2015) took place in New Zealand which has a 10-year statutory storage limit beyond which embryos cannot be stored unless an exemption is granted. Embryo donation became available in New Zealand in 2005, applying very specific guidelines set by ACART (the Advisory Committee on Assisted Reproductive Technologies set up under the ‘Human Assisted Reproductive Technology Act 2004’ (NZ)). These guidelines provide that embryo donation may be used to create full genetic siblings in no more than two families, and donors and recipients must meet and undergo joint counselling to negotiate their wishes and expectations regarding disclosure, information-exchange and possible contact before proceeding with an application to the centralized Ethics Committee on Assisted Reproductive Technology that must approve each donation.

In Australia embryo donation has been taking place since the late 1980s under varied legal regimes across the different states, none of which have imposed joint counselling with donors and recipients, nor mandated the content of embryo donation counselling, required centralized pre-approval of embryo donation arrangements, or drawn directly upon adoption frameworks (Millbank et al., 2017). While all Australian clinics have been required to utilize identifiable gamete and embryo donors since 2004 (NHMRC, 2004), the use of centralized mandatory donor identity registers and voluntary identity registers, and their conditions of access, vary significantly across the various states and territories (Millbank, 2014). Originally three, and now only two, Australian states impose statutory time limits on the storage of embryos (currently Victoria and Western Australia; previously South Australia: Karpin and Millbank, 2014). Notably only one of the donors in our study resided in a jurisdiction with a statutory storage limit at

the time of treatment, and this limit had not yet been reached at the time he donated: thus none of the donors in our study donated as an immediate alternative to mandated disposal.

The other Australian study, by de Lacey (2007a), was undertaken in South Australia at a time when a statutory 5-year embryo storage limit was still operative (with the possibility of a 5-year extension) followed by mandated disposal. Thus de Lacey’s finding that participants elected donation as the ‘least worst’ option, in contrast to our finding that donation was positively desired as the best option, can be explained by the operation of statutory storage limits pressuring patient choices.

Our study drew responses from multiple Australian jurisdictions and clinical sites, operating under different laws and clinical protocols. Taken together, the interviews with embryo donors, would-be donors and recipients reported on experience in five jurisdictions—the Australian Capital Territory, New South Wales, Victoria, South Australia and Queensland—and across 11 clinical sites, with a wide range of clinical protocols concerning recipient selection, counselling and information exchange. While most donations had occurred within 5 years prior to interview, four donations took place in the 1990s under conditions of anonymity.

This paper explains the broad findings of our study and highlights an important new finding: that jurisdictional regulatory difference is itself responsible for shaping not only the choices of interviewees to donate but also the type of language used and the response they have to embryo donation. Researchers in this area must therefore be wary of translating findings across other jurisdictions.

Materials and Methods

Recruitment

A multi-method recruitment process was developed, using both clinical avenues and broader advertising to the public. Australian fertility clinics were identified through the online Reproductive Technology Accreditation Committee list of accredited fertility clinics and contacted initially by email and then by phone. Clinic directors and, where available, clinic research coordinators were asked to pass along details of the study to patients who, according to their records, had experienced having embryos in storage. Eight Australian clinics (in New South Wales, the Australian Capital Territory, Western Australia and Queensland) provided recruitment support to this project.

Any potential bias associated with the clinical referral process was corrected through pursuing alternative recruitment methods. These included targeted print advertisements, posts to a variety of online fertility forums, and the authors’ own project website and media comment. These proved effective in garnering participation from a wider and multi-jurisdictional patient pool.

Volunteers were invited to participate through either engaging in face-to-face or phone interviews. Interview duration varied between 30 and 90 minutes, with most lasting around 60 minutes.

Data collection and analysis

The main data collection occurred over a 2-year period beginning in July 2010 and concluding in July 2012 with three additional interviews between September 2015 and September 2016. All interviews were transcribed verbatim and checked against recordings for accuracy. Quantitative data collected through the surveys were statistically analysed with the aid of SPSS (IBM, NY, USA). Qualitative data both in surveys and interviews were subject to thematic analysis. Each member of the research team

undertook multiple readings of interview transcripts and survey open responses both throughout the data collection period and afterwards, coding for emergent themes. Close attention was paid to repeated discursive and narrative frames within the text, particularly in relation to how participants described their decision-making processes, and mismatches between participants' understanding of their rights and options and the existing legal frameworks. Identified themes were then subject to comparative analysis among the entire research team to ensure uniformity of interpretation.

Participants

Of the total pool of participants we refer to above, 11 interviewees had donated embryos for the reproductive use of others and 6 interviewees were the recipients of donated embryos. An additional nine interviewees had attempted to donate, or expressed a strong desire to donate, but had been prevented from doing so. This pool of participants, though small in absolute terms, is comparable to the other two Australian and New Zealand qualitative studies (de Lacey, 2007a; Goedeke and Payne, 2009) and has the unique advantage of addressing donation practices across multiple clinical sites under distinct legal frameworks in each state.

Of the 11 embryo donors all were in heterosexual relationships at time of their donation, although one had since divorced. We spoke to three men as sole interviewees, and one man and woman were interviewed together as a couple; the rest were individual women. Ten donors had donated to people who were previously unknown to them through the clinic system, although some had met as part of the process or formed relationships since then. One donor, Brooke, had recruited her own recipient through an internet forum. Four of the donations took place prior to the introduction of identity disclosure rules in their respective jurisdictions.

Of the nine would-be donors, all were women: five had been in lesbian relationships at the time of treatment (although one had since separated); three had been in heterosexual relationships at the time of treatment (and one had since separated) and one had undertaken treatment as a single woman. Four interviewees strongly wished to donate and had actively pursued this through their clinic, but were ultimately prevented from doing so. Two women were very advanced in the process in that they had undertaken counselling, medical tests and signed consent forms but were excluded from donation based on medical factors. One woman was excluded at the counselling stage based on psychological factors. A fourth woman had repeatedly phoned her clinic in an attempt to commence the donation process but had not received any follow-up from the clinic. In addition another five interviewees expressed a strong desire to donate but had been told that they were unable to do so for reasons including that: they had utilized donor sperm in their own treatment; their partner would not consent or the relationship had ended; or because their clinic simply did not facilitate donation.

Of the recipients, all six were in heterosexual relationships at the time of treatment; one interview was with a couple, one with an individual man and the other three with women. Two women and one couple had self-recruited their donor; the two women from distant friends or acquaintances, and the couple through advertising in a magazine. These four recipients were still pursuing additional donation arrangements at the time of interview. The remaining two embryo recipients had both utilized donor embryos through their treating clinic after unsuccessful autologous treatment, had also been unsuccessful with donor embryos and had decided not to undergo any further embryo donation attempts at the time of interview.

In total, participants reported on 15 completed donation experiences; of which nine had resulted in offspring to the knowledge of the donor.

Ethical approval

Ethics approval to conduct this research was obtained through the University of Technology Sydney Human Research Ethics Committee

(Reference Number: 2009–262A and 2015000094). Written informed consent was obtained from participants and all information de-identified. Pseudonyms are used throughout.

Results

The study results demonstrate: firstly, the choice to donate was positively desired as 'the most attractive option' by embryo donors; secondly, that donor and recipient understanding of embryo donation do not prioritize genetic relatedness in their experience of kinship and thirdly, law, policy and practice shape the experience and understanding of embryo donation in ways that may make jurisdictional comparisons unsafe.

Differential understanding of donation

Our study found that although counsellors and clinicians presented donation as a 'difficult' and high risk choice, for those who planned to donate their embryos for reproduction, this framework was rejected (Millbank *et al.*, 2013a, 2013b). Rather, for most embryo donors, donation was positively desired. It was 'the most attractive option':

'[Donating to others] was a really easy choice for us... We had the expectation that we'd never have children and then bang, miracle of science we actually did. I think we just both have a lot of compassion for other people in that situation... it was a clear cut decision for us that we had these embryos, we weren't going to use them and someone else would value them immensely and that was quite easy.' [Scarlet, prevented from donating]

Several donors reported that the choice to donate was 'easy' or 'obvious'. For instance, Roger observed:

'We discussed all the options... we couldn't really go with the disposal because we got... such a lot of love and fun out of our kids, it just seemed such a wicked waste to dispose of those things... So we said well you can't just waste good quality embryos and we were not concerned with the sort of aspects - and I'm not trying to run other people down because it depends on how you see the world - but we didn't have the sort of ethical dilemmas that other people seem to have with this.'

This cohort of donors was very motivated. It is notable that of the 11 donors and 6 recipients, 13 reported that it was they who initiated the donation process. Of the donors only Gwen and Angie, both of whom donated in the 1990s, reported that it was the clinic which initiated contact and suggested donation to them. Of the recipients, two had been offered donated embryos by their clinic, in the 2010s, after long treatment processes including multiple pregnancy loss.

Several participants reported that their clinic made a practice-based refusal of donation which had not been apparent when they commenced treatment:

'When we approached [our clinic] about donating the embryos they just said to us, "Oh no, no we don't do that" ... Then, in that same week, almost coincidentally ... I saw [a] magazine had an article about IVF and donations ... It talked about how [our clinic didn't] do donated embryos, but [another clinic] do. I thought that was a timely article. So that week we phoned the clinic back and said well, but [this other clinic] do it. They said no problem; we can transfer your embryos over to them; but we don't do it. We were both a little miffed that they actually didn't inform us of that when we inquired about donating them.' [Sean]

It requires a very high degree of information, motivation and effort on behalf of donors to pursue embryo donation when their treating clinic

does not facilitate it. Three completed donation arrangements in the study took place when donors transported their embryos to another clinic.

The ability of donors to separate genetic links from notions of kinship

Our study participants were very clear that a child born through their donated embryos was not 'my' child but was instead the child of the recipient couple. The distinction between 'my' or 'our' embryo and someone else's child was the knowledge that another woman must achieve and carry a pregnancy. Several donors offered this explanation of how the value in the potentiality of embryos differed from 'life' and from children:

'Without Kim [the recipient mother] they would not exist.' [Bridget] '...it's a gathering of cells with amazing potential but you need somebody to bring that out and that's a recipient.' [Georgina] '...she's somebody else's daughter.' [Gwen]

In our study embryo donors did not conflate genetic links with an understanding of themselves as related by family. They acknowledged their role in the creation of the child but identified the connection forged by gestation and parenting as being 'real' parents. Roger noted that an acquaintance had characterized embryo donation as adoption and had responded that this was a 'nonsense view', adding 'I regard the people who gave birth as their parents, their rightful parents'. In direct contrast to Goedeke et al. (2015) study, we found that a social tie between the donors and recipients was not seen as immutable, but rather negotiable.

Of the 11 donors, only one had met the recipient couple in advance of the donation and undertaken joint counselling. Many clinics passed letters between donors and recipients and this allowed a range of information-sharing, including photos of children and updates, which did not necessitate identification of the parties (the so-called 'letter box' service). In two cases this had led parties to self-identify and make direct contact through phone or email, with varying levels of in-person contact and involvement thereafter. It was female members of couples who initiated both direct and indirect forms of contact between recipients and donors, whereas male partners were either opposed or reluctant. This is an area where further research might be warranted.

Openness to contact, information sharing and social relationships were seen as 'leaving the door open' to recipients, and subsequently offspring, to 'answer questions' and to provide a 'normal story' to their own children about their family form. Of the four donations that took place in the 1990s under conditions of anonymity, two did not result in any offspring. Of the other two, Bridget had made contact through her clinic letter box service and maintained a warm and ongoing relationship with the recipient family; whereas Gwen had received very limited information from her clinic and had joined a voluntary registry in an attempt to make contact.

Among embryo recipients, there was a range of views on early contact, or ongoing contact in the case of donors who were already known. Both Zara and Beatrice had fairly distant pre-existing relationships with their donors but had maintained contact with the female donor and her children on the basis that this would be 'more comfortable' for their own children as they grew up with the knowledge of the circumstances of their conception. Ava had negotiated agreements

with two previously unknown embryo donors, but had not yet conceived, and expressed herself as 'open' to contact which had been requested by the female member of one donor couple. Ava's husband Phil, however, was opposed to contact.

Similarly, Brooke, the only donor who had self-recruited her own previously unknown recipient had wanted annual contact between the families:

'[So] maybe they grow up knowing this child so that we can say, "oh yeah Bob, we helped Bob's parents to have him and he's" – yeah, something like that – to say, yeah, to say we helped someone, so that they know there's a connection...like distant cousins or something...because I didn't want them to get a shock later on.'

Discussion

Our findings vary slightly from the other Australian study de Lacey (2007a), and more markedly from the recent New Zealand study (Goedeke et al., 2015), as to motivation for embryo donation and understandings of kinship. We attribute these differential findings to the varied regimes within which the interviews took place. Our findings as to motivation, where our participants positively desired embryo donation, depart from de Lacey's (2007a, 1757) finding that donation was 'driven by avoidance of the worst possible outcome' and Goedeke's finding (Goedeke et al., 2015) that it was a hard choice. Unlike interviewees in those two studies, our participants were not faced with mandated disposal after a statutory storage period.

Embryo donation in New Zealand is a highly centralized process closely mapped from adoption law and policy with mandated counselling and approval processes (Goedeke et al., 2016), whereas the Australian experience varies more in practice and policy as there is little prescriptive legislation concerning the donation process (apart from that establishing identity registers). Indeed Goedeke's interviews with counsellors found that they had urged embryo donation participants to undertake adoption courses run by the Child Youth and Family Agency in New Zealand. Counsellors viewed participants who had undertaken this education as being much better equipped and making their own jobs 'much easier' (Goedeke et al., 2016). The Goedeke study found that both donors and recipients used the adoption metaphor and biological kinship to describe the longer term implications of having a genetic child separated from and raised by another family (Goedeke et al., 2015) and concluded that the gestational role was seen as secondary by recipients to that of the genetic connection of the child to the embryo donors.

These findings stand in contrast to our study in which participants emphasized the gestational role and did not see donors and offspring as related. We ascribe this significant differential finding to the open adoption model which pervades the New Zealand scheme of embryo donation (Goedeke et al., 2015; Goedeke et al., 2016).

Australian clinical practice in donation is diverse (see further Millbank et al., 2017). In only one case did previously unknown donors and recipients meet in joint counselling prior to consent to donate; although others met later. In the case of donations in the 1990s, recipients chose donors from a small selection of written profiles, in a fashion similar to the general practice in gamete donation. More recently, a number of clinics reversed this process and presented donors with a number of detailed recipient profiles (referred to as 'applications' by Sean) and

asked donors to choose from them. Other clinics chose recipients themselves, with some first requesting that donors elect general criteria (such as marital status and age range) to narrow the selection.

Although the New Zealand 'adoption model' includes joint counselling and open disclosure, (Goedeke and Payne, 2009), where 'in effect donor and recipient couples thus select each other' (Goedeke *et al.*, 2015) the majority of donors in our study did not desire this, for reasons including: not wanting to 'choose' recipients, believing it put too much pressure on recipients to seek approval, and 'because you can't judge someone on how they might look' (Gwen).

We therefore conclude, in accordance with de Lacey (2007a), that an 'open adoption model' and the use of adoption language should not be imposed upon embryo donation (Frith *et al.*, 2011). Instead our findings suggest that there is no suitable universal donation model appropriate to the experiences of all donors and recipients. On this basis we propose the development of flexible, elective models for donation that reflect the variance of donor and recipient experience and needs with varying degrees of openness or contact explored through counselling. Legislative models should facilitate this flexibility rather than impose a unitary approval system.

Conclusion

Despite consistent findings in the research literature concerning patient unwillingness or inability to donate embryos for the reproductive use of others, remarkably little research has been conducted on those who do donate embryos, and on those who receive them. This study contributes to that neglected field, relating and analysing interviews with 11 embryo donors, 9 would-be donors and 6 embryo recipients. The authors found that donors' and would-be donors' ultimate decision in favour of donation was not difficult in the way the literature had previously suggested and did not reflect decision-making based on 'least worst' scenarios compared to other dispositions. Indeed, donation to others was positively desired; for a number of respondents it was actively pursued.

Patient views and subjective experience of donation are an important question for qualitative research, but it is one that does not occur in a social or legal vacuum. Embryo donation and destruction is influenced by a number of external factors, including laws which limit the time embryos may be stored, as well as those which impose counselling and approval processes and provide or require donor identity disclosure. Moreover, variation in clinic-based donation models and practices impact upon willingness to donate (de Lacey, 2007b).

Policy and practice around embryo donation varies significantly internationally. With some jurisdictions prohibiting it, others allowing it under conditions such as identification of donors, and others having very little regulation (de Lacey, 2007b; Blyth *et al.*, 2011; Frith *et al.*, 2011; Takahashi *et al.*, 2012). For this reason, while international studies are interesting points of comparison, it is important to be aware of the possibility of jurisdictional difference, both legal and cultural (Takahashi *et al.*, 2012).

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Authors' roles

All authors participated in the research design, interviews, coding, analysis and authorship.

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Conflict of interest

None declared.

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