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Understandings and experiences of ‘open’ embryo donation in New Zealand

Sonja Goedeke

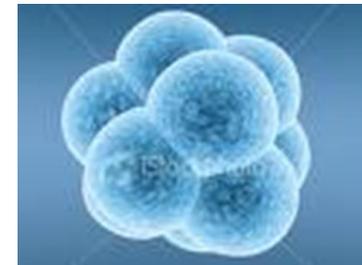
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Conflicting views and controversy

- ▶ Embryo donation (ED) as: Cost effective, practical, technically straight forward, viable solution for both donors and recipients

VERSUS

- ▶ ED as risky, uncertain, a “dangerous experiment” (Guichon et al., 2010)



- ▶ Note:

- Less than 10% of those with ‘surplus’ embryos proceed with ED (Blyth et al., 2011)
- Donors: More often contemplated than undertaken; majority change their minds (de Lacey, 2005, 2007)
- Recipients: Anticipated demand has not materialised ? (Richards et al, 2012; MacCallum & Golombok, 2007)
- Legislation and practice varies internationally: ED prohibited or restricted in some jurisdictions; where permitted, practices include anonymous donation, conditional directed donation, ‘open’ donation
- Lack of follow-up studies - complicated by anonymous donation practices
(Frith et al, 2011; MacCallum & Golombok, 2007; MacCallum et al., 2007; MacCallum & Keeley, 2008,2012; Paul et al., 2010)

The NZ Context



Guidelines

- ▶ Embryos must be ‘surplus’ to requirement
- ▶ Embryos must be formed from donors’ own gametes
- ▶ Embryos donated to one family only i.e. full genetic siblings in no more than two families
- ▶ Recipients must be infertile
- ▶ ‘Open identity’; encourage access to genetic information
- ▶ Mandatory individual and **joint** counselling of donors and recipients: ‘Mutual selection’ (Counsellors facilitate the process)
- ▶ No financial gain
- ▶ ECART (ethics committee) application

(ACART, 2005, 2008)

Study context:

Timing

- ▶ ED available since late 2005
- ▶ ED has had a relatively low uptake in NZ to date - 54 applications by (mid 2012) **BUT:**
- ▶ In November 2014, the 10 yr storage limit imposed under HART Act (2004) took effect, compelling decision-making for embryos reaching their storage deadline
- ▶ ACART (Advisory Committee ART) review of ED guidelines, 2015
- ▶ Interest in NZ policy/practice outcomes: Disclosure and open identity; 'mutual selection' practice and implications for future outcomes



Study method:

- ▶ Interviews with 22 donors (10 couples, 2 individuals)
- ▶ Interviews with 15 recipients (5 couples, 5 individuals)
- ▶ Policy, guideline, legislation analysis
- ▶ Interviews with 9 counsellors facilitating ED

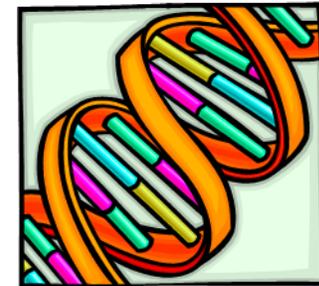
From across NZ



Ethical approval: Central Regional Ethics Committee
CEN/11/12/071 **Date: Feb 2012**

Results: 1. The significance of genetics

- ▶ Genetic link between donor and donor-conceived offspring seen as bestowing immutable social ties
- ▶ Genetic makeup of child seen as significant in terms of determining physical and psychosocial characteristics and conditions
- ▶ Access to genetic knowledge seen as critical for physical and psychological wellbeing and identity



Donors: The centrality of genetics



Donors

Child constructed as still “partly theirs”, and/but...

- ▶ Makes ED a very difficult choice; ambivalence and regret
- ▶ Assume moral responsibility for well-being of child
- ▶ Therefore:
 - ▶ Wish to select suitable recipients (‘good’ parents)
 - ▶ Wish to select best parents for this child with his/her genetically pre-determined characteristics (that ‘fit with’ the donor family)
 - ▶ Thus: Parents that are ‘just like us’ or ‘fit with us’
 - ▶ Desire open identity and disclosure, with a degree of information-exchange and ability for ongoing contact

Grace: People say, ‘How many kids have you got?’ Well (my husband) will always say 3, and then you have to explain. Jack: And I say, ‘We’ve got 2 here, and 1 in (area) that’s ours, or, sort of ours’

Jonathon: Because you’ve got to think, ‘Well this is silly! We can’t be thinking like this.’ You can’t dwell on, ‘this is your baby’ really... but when you are holding the baby it’s a bit different.

Grace: As much as we have no say in what happens with that child’s life, we still have an interest, and we want to make sure that they are doing... that B is being well looked after, and stuff like that.

Recipients: Significance of genetics



Recipients

Child constructed as theirs, but also “shared” – acknowledge connection to donor family

- ▶ Recipients had tried to have their ‘own’ children first
- ▶ Grief, loss, ambivalence
- ▶ Concerns about: parent/child bond; attachment between donors and child; parenting authority
- ▶ Some concern about genetic make-up of child (What are we going to get?)

BUT: These issues can be worked through

- ▶ Question becomes: How do we best parent a child given his/her unique background, of having ongoing ties to another family?
- ▶ Disclosure and openness (how best to manage)

Kieran: Yes, it's challenging, absolutely, and a lot of people just want their child, they want it to be just theirs, but you have to start off and say 'Well, this is the way it is'.

Zelda: I thought, 'I'm going to get a child. It's going to be my child - end of story.' And then all of a sudden it was, but that's not the way it is, of course it's not.

Wendy: X has kind of got two families I guess....

Beth (R) : I thought, 'Oh my God, I've got this life growing inside me that has absolutely no genetic connection at all'....and that took me a bit to get my head around. That was probably the biggest thing, because the other stuff (donor sperm)- it was still going to be partly me....This child would be genetically nothing to do with me at all, and I felt like an incubator, and I didn't really know how I felt about that. So that was where I said, 'What have I done, what have I done?'

2. Parallels with adoption experience

- ▶ Both donors and recipients draw on an ‘open’ adoption metaphor to make sense of and manage the significance of genetic ties: Embryo adoption
- ▶ This provides a familiar model for family building (many have experience with adoption; reassured by other party’s experience)

Brenda (D): When you have egg or sperm donation, it's half of them, belonging to them. But with embryo, like adoption, it's completely not theirs.

Brian (D): It's not a sperm or an egg. You just simply can't be entrusted with another person's child.

Neil (R): While everyone calls it embryo donation, we call it embryo adoption. We've adopted a little life, or about to.

Tanya (R): We'd be growing it. Just a very small baby, an early adoption. Grow your own adoption!



Donors: Adoption 'light'

- ▶ Framed as easier emotionally than adoption which involves the relinquishment of child that donors have gestated, given birth to, formed attachment
- ▶ However, metaphor makes transparent the longer-term implications of donation: Having a genetically-related child raised in another family
- ▶ Reinforces construct of embryo as “my/our child”
- ▶ Highlights issues of concern:
 - ▶ Concern about lack of formal assessment of recipients' suitability to parent in ED
 - ▶ Assumption that adopted children have greater access to information about genetic background (less able to conceal; more likely to disclose)
 - ▶ Concern that offspring can access information about donors only if recipients disclose, and permit information-exchange

Brian: We thought home studies would have been done. We just can't believe that a home study is not done for embryo donation. It's not a sperm or an egg - This is a human life that we have already created. ... you just simply can't be entrusted with another person's child, albeit at embryo stage, unless you pass criteria.

Jack: At the end of the day it doesn't mean squat does it? Because if (our recipients) move to Timbuktu, we can't do a damn thing about it.

Recipients: Adoption ‘with benefits’



- ▶ Opportunity to experience pregnancy, birth, parenting of young child

Thus:

- ▶ More like a ‘normal’ family
- ▶ Attachment and bonding promoted
- ▶ Ability to control prenatal environment (even ‘modify’ genetics)
- ▶ Legal status as parents
 - ▶ “More the parent”
- ▶ Greater success rate

Tim: It seemed to be full of pros and no cons. We still got to experience the pregnancy, being able to go through a birth like any other normal couple

Deborah: You’ve had that chance to bond and grow with him, and you know exactly what you’ve put into your body to produce this baby.

Leanne: Physically everything that went into that child to grow its brain, to grow its fingernails, its skin, was going to come from me. So that was my child.

3. ED as building extended family



- ▶ Donors and recipients refer to position of donors in relation to offspring as extended family: terms such as aunts, uncles, god parents, in-laws

Donors

Can maintain interest in child's life, have some degree of involvement, may express support and be available, BUT with clear boundaries; no "rights"

Recipients

Assume full parenting authority, but free to involve donors as desired.

Children

Allows sibling relationships to be acknowledged and actioned
But: does not assume any particular rights or obligations

And for other family members...

Pamela (D): We don't want to be Z's parents. We want to be Uncle and Aunty that can watch Z grow, make sure Z is safe..

Lance (D): Like godparents...in the background
Roy(D): In a way it's a marriage of a family. Yeah, to me it's more like your in-laws. You certainly are unwise to get married to someone if you absolutely can't stand the in-laws, regardless of which side it's on! If you don't like them, then you need to be very aware that that's going to be a problem, and it isn't going to go away.

Wendy (R): When we talk to others, we talk about our donor family... X will always know that X has these genetic relations, and that X has kind of got two families I guess. But we are x's family, and these people are people that are there if X wants to get to know them, and we are friends.... Actually, we call them family.

ED as building extended family



- ▶ Range of information exchange and contact arrangements: Social media, occasional contact e.g. for special occasions; a few times a year
- ▶ Actioned at different times (for many, from the outset)

John (D): We definitely try not to be too intrusive or anything, but we let them know that we are really happy and proud of what they are doing to alleviate any fears that they may have that we are wanting B, or anything like that.... I try not to send birthday presents on B's actual birthday, because that's their time with B. That's B's family time, and we always take a present every time we see B. We don't want to steal their thunder.

Lance (D): But on the other hand we have also said that if something ever happened to them, we would gladly take A as our own. And financially if A was in trouble, we would also certainly consider helping out because we do feel quite a strong connection with A, although A's not our child

Wendy (R): But the whole way through, our donor family were very supportive of us. We felt like we shared the journey with them. There are not very many other people who have done this, so we don't know any recipient families. We haven't met anybody who has been through this, but our own experience is that our donors have been with us through it.

4. ED as gift-giving versus mutual exchange

- ▶ Donors and recipients may draw on constructs of ED as a gift
- ▶ Evokes powerful dynamics of obligations and counter obligations:
 - Donors may expect reciprocity (NOT financial): Acknowledgement of gift given e.g. contact arrangements honoured
 - Recipients may feel indebted; obligated
 - (Recipient guilt when ED not successful)
- ▶ Less an issue when donors are able to construct their act as one of expressing thanks for gift they have received
- ▶ However: Embryos also framed as ‘inalienable gifts’
- ▶ Framing ED as mutual exchange:
 - Donors benefit through having solution for surplus embryos
 - Recipients are enabled to have children
 - Working towards common, shared goal



▶ 5. ED as last choice/ last option

- Donors: Ambivalence, regret - may affect ongoing emotional wellbeing and D/R relationship (*“We had no choice really”*)
- Recipients: Feel compelled to try; some concerns, although willing to undertake
- Relief for many when not successful

▶ 6. ED as novel practice

- Pioneers
- Anxiety and uncertainty
- Place great deal of weight on role of counsellors/clinic and ECART



Understandings of embryos/embryo 'status'

- ▶ Previous research suggests that ways embryos are seen important in decision-making e.g.

Embryos as collections of cells - destroy ✓ ; donate ✓

Embryos as children - destroy or donate?

- ▶ Could construct embryo in multiple ways:

Not necessarily an issue with destroying embryos/cells per se, however:

- ▶ Life potential = resource
- ▶ Investment: Time, financial, emotional and physical energy, also 'gift' and intentionally created
 - Desire to use, not 'waste'
- ▶ Human/*a* baby - thus need to respect, value
- ▶ Key issue in decision-making: *Our/my* baby/child - donors emphasise what the embryo will become if ED is successful



Role of counsellor and ECART

- ▶ Safety mechanisms/sounding board versus ‘big brother’
- ▶ However:
 - D/R cannot access counselling to full extent (blurred counselling roles: Assessment versus counselling)
 - Assume degree of selection and gate-keeping
 - Some hold clinic/counsellors and ECART responsible for longer term outcomes
 - Legal requirements reinforce notion that ED has been ‘approved’ and donors/recipients found suitable for this arrangement - may be reinforcing ED as adoption metaphor



Implications/questions



Donor - recipient relationships

- ▶ Need for clarification of information-exchange and contact expectations, boundaries, rights and responsibilities
- ▶ Need for access to ongoing support mechanisms e.g. counselling, support groups
- ▶ Should there be more opportunity for contact prior to making a decision about ED to ensure that donors and recipients can work together?

Suitability for ED

- ▶ Should recipients' suitability to parent, as well as donors' ability to manage the implications of ED, be assessed?

Disclosure strategies

- ▶ Should measures to ensure disclosure of donor conception, such as a birth certificate annotation, be introduced?

Role of counsellors: Assessment versus counselling

Clarification of role of ECART (role in child welfare?)

Cryopreservation/storage

Financial considerations

Balancing...



- ▶ The needs and rights of individuals/ adult parties - reproductive choices and decisions, ways to have families, make choices about their body parts and tissues
- ▶ The needs and rights of children/siblings, families
- ▶ ED as ‘treatment’ for infertility and solution for embryos ; the intersection of health and welfare concerns and sectors

Some interesting issues:

- ▶ Men involved in study
- ▶ Donors who subsequently go on to have further children
- ▶ Second ED attempt
- ▶ Donors wishing to donate to family or friends (medical eligibility requirement)
- ▶ Longer-term follow-up
- ▶ Blurring the boundaries:
 - Donor high emotional intensity
 - Child of different sex
 - Concern regarding parenting ability



Factors:

- ▶ New Zealand context: Treaty of Waitangi obligations; customary Maori beliefs and values; emphasis on genealogy and whakapapa
- ▶ Small population size: perceived risks of unknown consanguinity
- ▶ Adoption history and open adoption practice
- ▶ Fertility journey and reproductive history
- ▶ Financial issues



Conclusion

- ▶ Has the potential to offer a unique solution both for ‘surplus’ embryos and those wishing to build a family
- ▶ However:
 - Complex and challenging
 - Negotiating genetic, biological and social aspects of parenting and reproduction
 - “Holding on, and letting go”
 - Longer-term outcomes uncertain - Ongoing follow-up highly recommended
 - Some very positive outcomes to ‘open’ donation, disclosure as norm and ‘extended family’ contact, BUT also some ‘red flags’
 - ED requires measures to ensure that it is practised in a [safe way](#) that promotes the longer term health and wellbeing of all parties
 - Caution...

