Embryo donation for family building
Perceptions of donation, family and disclosure: A qualitative story completion study

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Definitions: Typical IVF scenario

M  F

IVF Child(ren)
Typical gamete Donor conception

- Partner
- Child(ren)
- Donor

Donor-conceived
Child(ren)

F
M

Half siblings
Typical Embryo Donor conception

- **F**: Partner
- **M**: Full siblings
- **IVF Child(ren)**
- **ED-conceived Child(ren)**
The ED ‘shadow family’

- Genetic M/F donors who are in relationship
- ‘Full’ siblings who are older
- Differs from adoption and other forms of donor conception
ED versus gamete donation and adoption

Ingredients
Egg/Sperm donation
Potential for life
Embryo donation
Life
Adoption

Obvious of course but demonstrates something of the in-between place of ED – between life and ‘not-life’
ED and ‘spare’ embryos

• Why are there ‘spare’ IVF eggs?
  – Imprecise science
    • # of eggs harvested
    • # of eggs successfully fertilised/grown into embryos
    • # of embryos surviving freezing/unfreezing
    • # of embryos vs. live births
• Can involve donated sperm/eggs paired
• Increasing #s of frozen embryos
  – UK = over 60,000 (Human Fertilization and Embryology Authority, 2016)
  – US = 600,000 in 2011
  (https://www.nightlight.org/spotlight/embryo-adoption-census-report-registration/)

Live birth from embryo frozen for 20 years
(Marietta, 2011, Health Law Perspectives)
Arguments for ED

• Practical
  – As successful than IVF using own genetic material or donated eggs
  – Cheaper than IVF


• Creates way to have pregnancy/birth/new born experience

• Avoids ‘problems’ of infant adoption
  – Less regulated than adoption
  – Offer of ‘perfect’ babies – genetically perfect

• Possible solution to issue of ‘left over’ embryos
Moral arguments for embryo donation: e.g. framing in terms of Christian pro-life debate

Snowflakes Embryo Adoption and Donation - Snowflake Babies!

“Before I formed you in the womb I knew you, before you were born I set you apart” (Jeremiah 1:5, NIV).

Just as each snowflake is frozen, unique and a gift from heaven, so are each of our Snowflake Babies. We hope to help each donated embryo grow, develop and live a full life.

- Nightlight Christian Adoptions pioneered embryo adoption in 1997 with the creation of the Snowflakes Embryo Adoption Program
- Over 450 babies have been born to their adoptive parents through successful Snowflakes placements
- Over 1,100 families have donated their remaining embryos through Snowflakes (sometimes referred to as leftover, excess, unused embryos)— allowing them to choose the family for their embryo gift
- Embryo adoption is a low-cost adoption option, allowing you to experience pregnancy and give birth to your adopted child
- Unlike other programs, Snowflakes has embryos available for adoption now
- There are now well over 600,000 embryos in frozen storage in the United States. Will you choose to donate? Will you choose to adopt?
BUT Conflicting religious views on ED


- **Buddhist** – belief life begins at conception; no ethical issue with IVF; preference for ED
- **Judaism** – recognises life after 1\(^{st}\) trimester; no ethical issue with IVF; preference for ED
- **Catholic** – moral issue with IVF; preference for disposal of ‘spare’ embryos
- **Islam** – recognises life after 1\(^{st}\) trimester; concern with maintaining genetic; lineage; favour donation for research
'Tricky’ legal perspectives on embryos = “not-things”

Recent judgement by the European Court of Human Rights


• “With this judgement the European Court of Human Rights has just indicated that in no case embryos can be considered as goods, as a thing. At the same time, the court did not say either that embryos are to be considered as persons.”

Contested legal status of ED

- Banned in some countries, including Denmark, Israel, Turkey, Norway and Japan.
- Japanese Society of Obstetrics and Gynaecology ‘prohibits embryo donation to other infertile persons or couples since it causes confusion in parent–child relationship and the child’s welfare needs to be most prioritized’ (Takahashi et al., 2012, p.1)
‘Tricky’ legal perspective on parenthood and genetics

- UK appeals court case where egg donor seeks parenting rights
- At the time of donating applicant was in a relationship with the twin's legal and gestational mother.
- On appeal, the court ruled that the trial judge had erred, by failing to properly weigh the importance of biological ties
- Ruling links ‘genetic parent’ to legal argument about welfare of child although donors are not – in British law - parents
ED research to date

**Overall = under-researched**

- **Decisions about embryo disposition**
  - Donation = least favoured option
  

- **Well-being of ED-conceived children**
  - Child outcomes = OK
  - Disclosure potentially an issue

  

- **Non disclosure due to concern about impact on parent-child relationships and stigma for donor-conceived child**

Is ED stigmatised?

Comment from parenting site

Not being the genetic parent of your child due to using donated eggs or embryos means facing difficult issues. You and your partner will need to consider how you'll tell your child about their genetic origins.

http://www.babycentre.co.uk/a1014397/egg-and-embryo-donation#ixzz3bRwr8kWK
Despite enormous clinical success, there are inherent shortcomings to the method. The recipient does not contribute genetically to the offspring and this is often a most difficult problem to reconcile.


Comment from academic journal
Dominant cultural perception of family as genetic (vs. social)

- Impact on donor-conceived people and their families is well documented in research – e.g. struggle to create sense of family/belonging in:
  - “the face of an increasingly unsympathetic popular culture that emphasizes the importance of genetic links” (Nordqvist & Smart, 2014: 28).

What about ED families? Recipients and donors?

ED a contested practice – tricky, complex, difficult – because of transgression of genetic understandings of family???
Research question

How are ED families (donors and recipients) ‘read’?

How is the act of donation understood?

How is family perceived in context of ED?

How is disclosure of ED involvement perceived?
Study method

• **Method = Qualitative Story Completion** (Kitzinger & Powell, 1995; Braun & Clarke, 2013)

• Not an essentialist reading of the data:
  “researchers can... interpret these stories as reflecting contemporary discourses upon which subjects draw in making sense of experience” (Kitzinger & Powell, 1995: 349-350)

• Suits research where you want to understand *social perceptions or understandings* of an issue
  – E.g. those drawn on by ED donors/recipient AND general public (including friends/broader family)

• **Excellent** for research where you’re interested in *assumptions*
Design

• Online qualitative survey
  – Donor stem
  – Recipient stem
  – Demographic questions

• Sample = UG students
  – Convenience
  – Potential contemporaries for ED adults
In writing your stories, it might be useful to know that in Britain, couples or individuals who donate embryos for family building donate them anonymously. No contact is permitted between donor and recipient families. However, a child born as a result of embryo donation can, once they reach 18-years-old, choose to contact their genetic parents.
Tom’s parents sat him down and told him that although his mum carried him in her belly, they are not his genetic parents. Instead he had been a frozen embryo that other people made and then donated to them... What happens next?

*Describe what happens over the next ten or more years....*
Davey and Emily have to make a decision about their three ‘left over’ embryos following successful IVF treatment. One option is to donate them to someone else trying to have a child... What happens next?

Describe what happens over the next ten or more years.
N = 125 but usable stories from 102; 80 recipient stories, 75 donor stories

- Age = mean = 21.6 years (range 18-60)
- 80% female
- 87% heterosexual
- 90% ‘White’ or ‘White British’
- 63% middle class; 30% working class
- 98% non-disabled
- 49% currently single; 39% ‘partnered’
  - 10 (8%) of the sample had children
  - no history of fertility treatment
Results

Focus 1: Perception of act of donation
Donation as an amazing gift

• Please believe Daddy and I when we say that we gave people an opportunity to have what we have as a family and that's a very special gift.

• To help someone create a family they potentially couldn't of had any other way was an amazing, selfless act.

• They said that the people who donated the embryo were very generous and they gave them something in their lives that they love very much and that they could never repay them for their generosity.
– I know I couldn't bear the thought of us chucking our potential children into the bin just because we couldn't give up our *selfish* worries and concerns, I think we both know the best thing to do is to donate them.

– *They can’t be hypocrites*, and have a child themselves though IVF and not allow another couple to experience the joy they will have.

– Their *selfless* decision was so important and should be a message that life should never be *wasted*!
Or...Donation = selfish, objectifying

- There are thousands of children around the UK that need a loving home and have already been born and will just be 'dumped' off onto society, not being given the life that they deserve. Why would someone, who wanted a child to love, then allow themselves to forget about all these children that need homes so his mother could more or less, be selfish, and carry him herself.
- He didn't see himself as a charitable donation either.
- He wants to know who his true parents are and why he was 'donated'. The term donate itself dehumanizes him.
Donation = abandonment

Donor parents – failure as a parent

• It feels like we're **abandoning** our own children before they've even been born, and imagine what they'd think of us as they grow up.

• If she had had a couple of drinks, Emily would get distressed, and liken it to **giving away a baby to a stranger** for no reason.

Donor siblings – it could have been me

The twins had always known about their parents donating their left over embryos but it was only when they reached a certain age that they started to comprehend the meaning of what that meant. "So you gave away your babies?" one of them questioned, anxiously. "**Will you give us away** to other grown-ups?" piped up the other.
ED child

– He's unsure as to whether or not to feel abandoned by this family who biologically, are his natural parents.

– At first he felt rejected by his biological parents.

– He doesn’t know if it is normal for him to want to know about his biological family, and if he should even want to. After all they gave him away.
Donation means lucky to be alive

• [Tom] asked: “So my genetic parents gave you guys the embryo so that you could have a child...me?” Tom’s Dad smiled and replied, “Yes Tom, and without them doing that, you may have not been born so you were very lucky.”

• She didn't have to go through all that trouble and get someone else's embryo to have him - the more Tom thought about it, the more he appreciated his mother for giving him a chance to be alive.

• Tom sits and thinks about this in his head, he is a happy adolescent and he is grateful he has had the chance to live and he wouldn't change this for the world.
Donation = existential uncertainty

The one thing that scares him the most is knowing that if his legal parents had not wanted him, his biological parents may have given the scientists permission to destroy him or to be tested upon in order to evolve stem cell research. He has conflicting thoughts about this...was he even really meant to exist if he was just a 'spare' embryo?
Focus 2: Perception of ED family
ED and real parents

**Donor parents are real**

• He is curious to track down his **real** parents and family relations.
• He wishes he could find his **real** parents and meet them.

**Recipient parents are real**

• Tom realises that his '**real** parents' are the ones that raised and cared for him and that he shouldn't be so concerned about genetics.
• His **real** parents were the parents he had known all his life.
Family is genetic

• For the next few days [Tom] was so upset that he barely came out of his room. He missed school and cried often. Even though he had 2 perfect parents that loved him as their own, he could not accept the fact that he was not actually theirs.

= explains why news of ED disrupts relationship with parents

Image from family genetic testing service
https://www.familytreedna.com/images/slider-ff.png
Family is about (genetic) similarities

• He wondered what they were like, whether they had had teased about red hair growing up, whether they were allergic to peanuts or hated the taste of strawberries like him.

• [Tom’s mum] finds it difficult as she feels like Tom is completely hers as she gave birth to him but when she looks at him she doesn't see herself or his dad in him as he doesn't have their genes.
Family is gestational

• For her it didn't really matter where the embryo came from as she still carried him and gave birth to him, so to her he was completely hers as she's known him all his life.

• We are your family we have raised you, I still carried you for nine months, I am your mother!

• Despite the fact we are not your genetic parents, we are still technically your biological parents as you were carried and fed inside my belly!
Family is social

• Tom knew deep down that even though there may be no genetic links, these were his real parents, they'd been the ones who picked him up when he scraped his knee as a child, who tucked him into bed at night.

• By the time Tom has left for university he has accepted the idea that family is more about who supports you than whose genetics you share and its only relevance is to his medical history.
Family is (social) similarity

• Tom up until this point had never had any suspicions that he wasn't genetically related to his parents, he was extremely talented at football just like his dad and had his mum’s incredible sense of humour.

• The twins are unsettled by the physical similarities between themselves and the stranger. Though they look like siblings, they have next to nothing in common, his accent is very different and he has very different views on things than they do.
Family is love

- Genetics don’t make a family but love does. So whoever loves the child that came from their embryo is that child’s family.
- [Tom] reassures his parent and family that he loves them and that they'll always be his family.
- What matters is that they love him very much, and that he's their son. "You're 100% our son and we love you very much, sweetie" his mum said. This made him smile and from then he did really believe that.
- *We are your family and we love you.*
Focus 3: Perception of disclosure
• They wonder as well, whether their parents love them as much as they would love their children if they had been conceived naturally, or whether having been conceived through IVF makes them "different".
• Even worse, he was not simply given birth to and 'given up' but a sort of medical experiment - to be a frozen embryo - is not what society considers normal.
• Not being conceived naturally makes [Tom] feel different, almost like he was a[n] experiment in himself...dehumanised.
• After finding out that he was once a frozen embryo, Tom starts to question his origin, is he really "human"?

*Stigma not about lack of genetic link*
Impact of stigma = fear of disclosure

• He did, on the other hand, feel a slight worry about telling this story to his friends. He was pretty sure he was the only one out of his friend group, or even, the school who had been a frozen embryo! And was his girlfriend going to think he was a freak now?? How would Tom have reacted to one of his friends telling him such a thing.

• He does not wish to tell others of his true comings into the world.... He is scared to tell others of this, he believes that society will reject him and cast him out as a freak as this is not a common situation.

• Tom also considered telling his friends at school about it, but when mentioning it to his Mum she was hesitant and said that sometimes not everyone can accept that you were made differently.

*Stigma is about ED as scientific & freaky*
ED is confusing

- *ED is something that is hard to understand and the news is confusing*
  - At first Tom was very confused as he couldn't get his head around what he has just been told.

- Lots of confusion in stories about what ED is – e.g. confuse it with egg donation or fostering
  - [Tom] asked some questions and became confused about the term test tube baby and thought he was an alien but his parents quickly corrected him.
Confusing how to describe

Lack of an appropriate language

– Tom becomes upset at the fact his 'parents' are not his genetic parents.

– As a teenager he needs to understand who he is and find his place in this world and he feels that the only way is to find out more about his "real" parents.

– [Tom] loves them as if they were his own parents [emphasis added]

– [Tom] will not treat his parents as if they weren’t genetically his but will continue to feel bonded to them as though they were [emphasis added]

– Use language of ‘birth’ and ‘adoptive’ parents
ED news is upsetting

• Tom is described as shocked (22 mentions), hurt, upset, sad, tearful
• News is depicted as life-changing
  – With this information everything has changed for Tom.
  – He will never be able to feel the same again, and that this had changed his life forever.
  – Tom remained calm, but was reeling inside. How could this be? Family was the one thing that was supposed to be true, the one thing in life that was constant.
Or...News is also not that important

• After a while the twins accept this and, other than they odd passing thought, the matter doesn’t really impact on their lives.

• Tom is confused at first as to what the process involves, but when he understands it fully, he deals with the information well and it does not have a significant impact on the families' life.
News is a betrayal; life now a lie

• Tom was shocked and disheartened by the news, he also felt very betrayed!
• Tom is shocked and slightly confused about what to do with this information as his whole life essentially seems a lie now.
• Tom couldn't believe what he was hearing. All this time his parents hadn't told him this fact about himself. Why? Did they feel ashamed? What were the reasons for keeping it a secret?

*Stories also depict parental difficulty about when best/how to tell*
News creates rift with parents

• He didn't blame his parents but he still felt hurt and as though he didn't really belong in the family.
• Tom is shocked initially as he had no idea that this was the case. He cries and is upset and needs reassurance that his mum and dad love him exactly the same.
• All the while, his mother and father worry at night about how they could lose their beloved child due to the shocking news, despite having raised him together from the beginning. Unfortunately, a rift is caused between Tom and his parents and he slowly drifts from them over a number of years.
News creates self-doubt

• [Tom is speaking to a peer Pete] 'I don't know man, it's all pretty messed up isn't it? I mean mum and dad have bought me up like any other parents would but I can't help but feel that my identity is lost.'

• Tom gets very upset. He is 15 years old and just found out that he is not the biological son of his parents. Thoughts are racing through his mind and everything feels so unreal. He starts to questions his identity and values. His adoptive parents keep explaining what happened, but Tom cannot hear a word - he is locked in his mind and thinking about his short life.
Discussion...
Framing of donation

What Is Embryo Donation?

Embryos are created through the Assisted Reproductive Technologies (ART). In order to minimize multiple pregnancies, excess embryos are frozen (cryopreserved) in liquid nitrogen for future use. Eventually, a caring and compassionate individual, an embryo donor, may decide to donate these frozen embryos. Rather than discard the embryos or donate them to science, the embryo donor believes that their embryos deserve a chance at life and a patient in need deserves a chance at parenthood. It is truly a wonderful and amazing gift.


Donation as gift-giving

Research on perceptions of donation

Disposition literature - Blyth et al. (2011) summary

- Disposition = very difficult decision and couples often change their mind
- Perception of the embryos as their 'virtual' or 'future' children = linked to reluctance to donate
- Perception of embryos as unborn children = found for those who do donate


Current study echoes research findings about donor concerns as well as pro-social narratives of donation

BUT new narratives e.g. personal meaning of donation – pertain to possible meanings for ED-conceived child which are currently un-researched
Research on framing of family in ED

• Qualitative synthesis including some ED Wyverkens et al. (2014) - found that in order to facilitate their experience of ‘normative’ family, ‘parents tend to “erase” the donor in their family constellation’ (p.14).


• UK pre 2005 ED study, McCallum (2009) - in comparison with parents who had adopted children, the ED parents did not place much significance on the ED donors - relatively unimportant to their family life


• New Zealand ED study, context of openness - Goedeke et al., 2015 - both donors and recipients drew on constructs of extended family to describe and make sense of their relations with each other, simultaneously placing emphasis on the importance of genetic links

Relative Strangers – (Nordquist & Smart, 2014) = how donor conception families made sense of family
• Deny/dismiss
• Gestational
• Similarity
• Social

Current study echoes research findings e.g. dominance of genetic ‘story’ of family but clear evidence of other narratives

ALSO new narratives – e.g. family = love
Policy on disclosure

- Australian state of Victoria – some of the strictest laws globally requiring donor conception disclosure
- Contemplating retroactive removal of donor anonymity

- The Victorian Government emphasizes that a 2012 Parliamentary committee 'found that knowing your genetic heritage is critical to a person's sense of identity, and [that] community views have also shifted in recent decades in line with this.'

Explains why the news is distressing
Current research suggests low disclosure rates in ED


More likely to tell if genetic links are greater


But will non-disclosure be viable in future?

Harper, J. C., Kennett, D. & Reisel, D. (2016). The end of donor anonymity: how genetic testing is likely to drive anonymous gamete donation out of business. Human Reproduction, 0(0), 1-6
Perceptions of disclosure

Narrative of genetic families understood to mean that late disclosure is very shocking

*ED is very meaningful – a very big secret*

*? support the importance of early disclosure*

*? lack of understanding of ED is a barrier*
What next?

• Broader social research on perceptions of ED
• Research with donors – adults/families
• Research with ED-conceived children
• Longitudinal research
• Impact work - researchers actively shaping social narratives
  – Web-based resources
    • Personal stories
    • Online Fora