Family relationships and disclosure in embryo donation

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“Blood” is thicker than water? (or: why we think genetics matter)

- Huge interest in tracing family trees
- Behavioural genetics
- Medical genetic diagnosis
- “Resemblance talk”/ “blood-ties”
- What about non-genetic parents?
  - Adoption
  - Embryo donation
Embryo Donation: Background

- Recommended when both of couple infertile or previous IVF attempts failed

- Currently in UK, majority of donor embryos “surplus” from another couple’s IVF treatment

- ~50-60 babies born p.a. through embryo donation
  - 2009 – 256 embryo donation cycles
  - 2013 – 693 embryo donation cycles

- Child raised by two parents to whom not genetically related
  - May have full genetic siblings elsewhere

- Some refer to it as “embryo adoption”
Embryo donation vs. adoption

- Legal mother is woman who gives birth to child and legal father is her husband

- “Embryo ‘adoption’ is a term that may be endearing and may even be accurate in a bio-psycho-social sense, but it is not accurate in a legal sense” (Crockin, 2001)

- Selection criteria for adoption is social and psychological; selection criteria for embryo donation is medical

- >5000 adoptions in 2014-15; average age 3y3m
1) Does the absence of genetic links matter?

- Evolutionary psychology
  - “Children are a parent’s most direct route to genetic immortality” (Bjorklund, Younger & Pellegrini, 2002)

- Absence of genetic links would influence quality of parenting and parent-child relationships
  - Attachment theory

- Does this result in more positive relationships in embryo donation and adoptive families than in genetically related families?
2) Does pregnancy make a difference?

- Embryo donation parents have opportunity for prenatal bonding and regulation of prenatal environment

- Associations between prenatal bonding and postnatal attachment

- Children do not experience physical separation from and relinquishment by birth parents

- Does this result in more positive relationships in embryo donation families than in adoptive families?
3) How are children affected?

- Some adopted children show raised levels of behavioural problems, starting around age 7

- May be due to adoption specific characteristics – biological factors, pre-placement history, understanding of concept of relinquishment

- BUT could be associated with lack of genetic relationships

- Does this also happen with embryo donation children?
4) What do parents tell their child?

Adoption

- Early days – adoptees not always informed but recognised this could lead to problems

- 1960s on – more child-centred open structure

- Continued with development of open adoption

- BAAF advice: “Children should be raised knowing they were adopted”

- Most adoptive parents begin to share the circumstances of the adoption at age 2-4 years
4) What do parents tell their child? Donor conception

- Early days – parents encouraged NOT to tell

- 1980s – less than 10% of sperm donation offspring told

- Changes towards openness in policy and regulation
  - Since 2005, donor conception offspring can trace the donor at 18
  - BUT parents have no legal obligation to tell child about donation

- HFEA advice: “It is advisable for parents to be open with their children from an early age”

- Do embryo donation parents tell their children, and if so, how?
What did we do to answer these?

- a) 17 embryo donation;
- b) 24 adoptive (placed before 12 months); and
- c) 28 genetically related IVF families

- Parents and children assessed on parent-child relationships and child development

- Teachers asked about child development

- Follow-up of study on children aged 2-5 (87% response rate)

- [Current study specifically on disclosure process:
  - 36 embryo donation parents: sampling aimed at “open” parent
  - 27 adoptive parents]
Measures used

- **Family relationships**
  - Standardised interview with parents obtaining detailed account of child’s behaviour and parent’s response (Quinton & Rutter, 1988)
  - Separation Anxiety Test to children (Wright, Binney & Smith, 1995)

- **Child socio-emotional development**
  - Strength and Difficulties Questionnaire (Goodman, 1997) to parents and teachers
  - Harter Self-Perception Scales to children

- **Disclosure of method of family creation**
  - Interview section based on previous research and areas of interest
Do non-genetic families differ?
Do non-genetic families differ?
Does pregnancy make a difference?

Over-involvement at 5-9 years

- Embryo donation
- Adoption
- Genetic
Does pregnancy make a difference?

Defensive responding at 5-9 years

- Embryo donation: 0.5
- Adoption: 0.2
- Genetic: 0.1
How are the children doing?

- Mothers’ reports:
  - No more difficulties in embryo donation
  - Adopted children higher on hyperactivity

- Teachers’ reports
  - Same pattern as mothers

- Psychiatrist’s ratings of mothers’ interviews
  - Higher proportion of adopted children with ADHD symptoms

- Children’s own reports
  - Adopted children rate selves as doing less well at school
Do parents tell their children about their origins?

![Bar chart showing the distribution of responses to the question: Not telling, Uncertain, Plan to tell, Told. The chart compares responses for embryo donation and adoption.](chart.png)
Why do some parents not tell?

- 70% felt “no need to tell”
  - “As far as we’re concerned they’re ours. I mean I carried them for 9 months”

- 50% concerned about family relationships
  - “You do worry that they might love you less or ask ‘where’s my real mum and dad?’”

- 30% wanted “to protect child”
  - “It would devastate her. She loves us so much”
  - “He’s not going to be able to find out so why make him think that Daddy and I aren’t his real parents?”

- Also, do not know what to tell
  - “It’s complex, it’s hard for adults to understand so how would he understand?”
Parents who have told child

► Being honest, not lying
- “How could you, you'd feel your whole entire life had been based on a lie. People have been lying to you all of those years, so I don't, I couldn't not tell him.”

- “I would be honest with them in every aspect of life so why would I conceal this bit?”

► The child’s life story
- “I think it is very important for them to know, because it’s...just a part of their story, a part of their life. It’s-you know...it doesn’t mean-it’s not-it’s...just different, it’s not better, it’s not worse, it’s just different.”
Choosing when to start disclosure

- Majority started when child was a baby

- **Benefits for children**
  - “they need to know at an early age so that it’s not a surprise to them when they’re growing up then it’s part of everyday language…”
  - “It was you know like subliminal learning. You will just hear, this, this little tape will play in your head when you’re older.”

- **Benefits for parents**
  - “I suppose trying out different words and different ways of telling them so that you feel very COMFORTABLE with it, and this, you know, that’s a good opportunity to do that on a 3 week old baby because they’re not responding…”
  - “I used to talk to him when he was a baby more for my own benefit because for the first few times that you talk about it it’s really emotional actually that goes to show that I did actually used to think a lot more about the donors then, but you sort of you almost need to desensitize yourself about it”
The stories parents tell - adoption

Common themes

- “The basic that we've told her is that they were very young when they had her, they weren't able to give her a good home, weren't able to look after her, weren't old enough to be able to make good decisions for her, and so the best decision they made for her was to find a home where somebody could look after her properly”

- “So we talked a lot about that with him, erm, around wanting a family not being able to have, erm, babies in my own tummy, erm, but, erm, but that we REALLY still wanted to have our own forever family, and that, he was, he was that person that special boy!”

“Difficult” areas

- “It's difficult, because you don't want to sugar coat it too much, because they haven't done the right thing by their baby, and the child's needs should come first, but you don't want the child to feel as though they weren't loved, either”

- Concern around managing contact with birth family, especially siblings
The stories parents tell – embryo donation

**Common themes**
- “Kind man and a kind lady”
- “I really wanted to have you so much and so did daddy and we were trying so hard and in the end we went to get help from that kind doctor that you have met”
- “Little bit of a woman’s body and a little bit of a man’s body and we mixed it all up in a, in a dish and popped it inside mummy’s tummy and you were born”

**“Difficult” areas**
- “Sperm’s a bit awkward [laughs]. It’s not like you sort of bandy that word around the school playground normally, so it’s a bit tricky really. Yeah.”
- “They’re too young to understand the difference between the sort of SOCIAL family and the biological family, in inverted commas for want of a better word.”
- Concern regarding donor “siblings”?
What does this all mean?

- Neither genetic links nor gestational links are essential for bonding.
- Emphasis on social component of parenting.
- Children raised by non-genetic parents not necessarily at a disadvantage.
- Telling children about their genetic backgrounds can be difficult.
- Some offspring still unaware of how they were conceived, or unable to identify donors.
Unanswered questions

- Will things change as children get older?
- Has the change in the law on donor identity had the desired effect?
- What do children really understand about the donors and other genetic relatives?
- How can we support and/or encourage parents in telling their children?