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# Psychological wellbeing of ART children: Long-term follow up studies

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# IVF children: Concerns



- Parents may treat their children differently
  - Overprotectiveness, unrealistically high expectations of children and of themselves as parents
- Others may treat their children differently
  - “I think my mother-in-law thought he was going to come out with two heads. She does love him, I’m sure she does, but there’s always been that little something....even when she came to the hospital after he was born, she didn’t pick him up.”



# Donor-conceived children: concerns



- Parents may not fully accept children as their own
- Secrecy about children's genetic origins may interfere with quality of parent-child relationships
  - Research on adoption
  - Family therapy literature



# Concerns about donor-conceived children



- ‘AID children may feel obscurely that they are being deceived by their parents, that they are in some way different from their peers, and that the men whom they regard as their fathers are not their real fathers.’

— Report of the Warnock Committee, 1984.



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# Longitudinal studies at Centre for Family Research



- European Study of Assisted Reproduction Families
  - Children born in mid-80s
- Millennium Study of Assisted Reproduction Families
  - Children born in 2000



# Research questions



- Does the quality of parenting experienced by ART children differ from that of naturally conceived children?
- Are ART children at greater risk for psychological problems than naturally conceived children?
- What do parents tell children about their conception?
- How do children feel about being donor conceived?



# Methods



- Multi-informant
  - Parents
  - Children
  - Teachers
- Multi-method
  - Standardised interviews of quality of parent-child relationships
  - Observations of parent-child interaction
  - Standardised questionnaires
  - Standardised tests with children



# European Study of Assisted Reproduction Families



- UK, Spain, Italy & the Netherlands
  - 116 IVF families
  - 111 DI families
  - 115 adoptive families
  - 120 natural conception families
- Families assessed when children were 6, 12 & 18 years





# Findings



- Higher quality of parenting in ART families
- Children showed high levels of adjustment
  - Even when they lacked a genetic connection to father
- Less than 10% of DI parents had disclosed genetic origins to their children
  - Due to fear that children would love them less

# Millennium Study of ART Families



- 51 egg donation families
- 50 donor insemination families
- 80 natural conception families
- Ages 1, 2, 3, 7, 10 and 14 years



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# Findings



- Positive parent-child relationships and high levels of child adjustment
- By age 7, only 39% of egg donation parents and 29% of DI parents had told child about donor conception
- Earlier disclosure of donor conception associated with more positive mother-child relationships



# Donor-conceived adolescents



- Most felt unconcerned about their conception
  - “I don’t think it really affects anything. I consider that my dad is still my dad”
- Many were interested in knowing who their donor was, or to meet.
  - But not all were



# Donor Sibling Registry Study



- Donor-conceived people search for donor to gain a better understanding of where they came from and who they are
  - To form a more secure sense of identity
- Those who found out about their donor conception when young were more likely to be accepting



# Conclusions



- ART children have good relationships with their parents and show high levels of psychological wellbeing
- It is usually best for children to be told about their genetic origins in their pre-school years



# Relevance to germline editing



- Openness with children from a young age is likely to be beneficial
- Openness is required in order to conduct long-term follow up studies
- What might we expect regarding children's psychological wellbeing?
  - Quality of family relationships matter more than how children were created
- What might children want to know?
  - What was done to them as embryos? And why?



# Informed consent



- At each phase of the study, written informed consent obtained from each parent for child to take part in study
- Verbal assent from children from age 5
- Written informed consent from children from age 14
- Consent to contact parents for future phases (which doesn't commit them to taking part)
- Consent to contact them through NHS central register
- Consent to contact them online (google, Facebook)





# Intergenerational studies



- No intergenerational studies have yet been conducted of ART children
- Intergenerational studies of children's psychological adjustment have been carried out
  - Avon Longitudinal Study of Parents and Children
    - Psychological and physical measures of development
    - Genetic measures
- Key challenge is sample attrition
  - From research on ART families, expect low levels of attrition as long as parents have been open with their children





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