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Exploring the 'lived experiences' of egg share donors: can women consent to share their eggs?

Original Citation

Golding, Berenice (2011) Exploring the 'lived experiences' of egg share donors: can women consent to share their eggs? In: 31st Annual conference of the Society for Reproductive and Infant Psychology (SRIP), 13th -15th September 2011, Nottingham, UK. (Unpublished)

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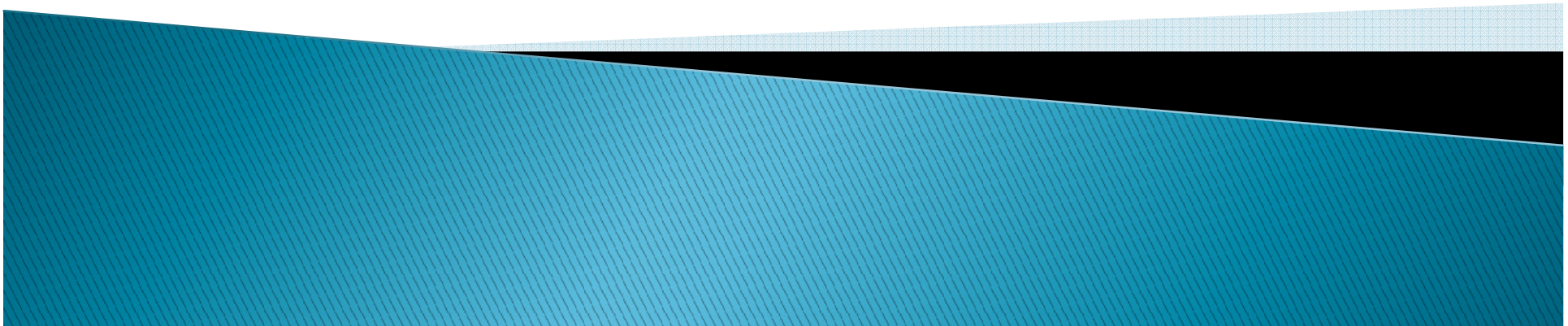
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Exploring the 'lived experiences' of egg share donors: can women consent to share their eggs?

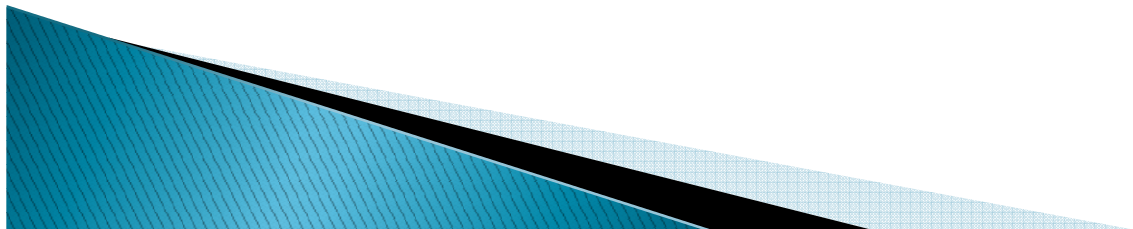
Dr. Berenice Golding
University of Huddersfield

Paper presented at Society for Reproductive and Infant Psychology Annual Conference,
13th-15th September 2011, University of Nottingham



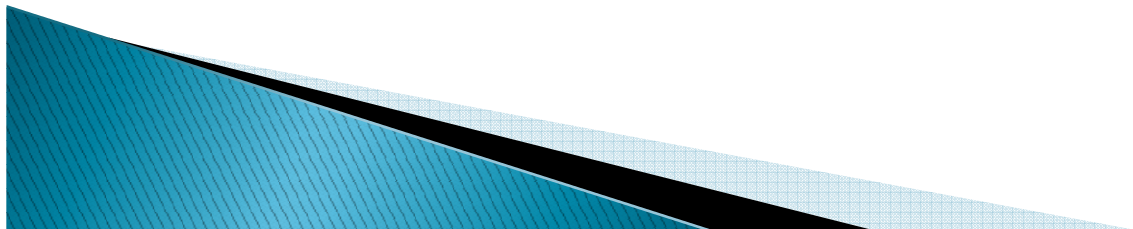
Aims and objectives

- ▶ To report on the findings main that emerged from an ESRC 1 +3 funded doctoral research studentship [PTA-031-2006-00262].
- ▶ Emphasis will be given to the emergence of 'invisible relationships' post-treatment.
- ▶ This will be discussed within the context of informed consent provision.
- ▶ The paper will demonstrate how egg share donors reconceptualise their involvement in egg sharing.
- ▶ It will argue that the potential future implications of egg sharing, need to be discussed, more thoroughly, with potential egg share donors.



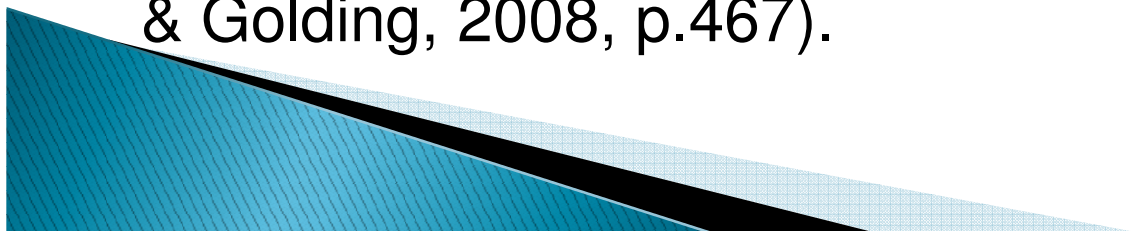
Background

- ▶ First successful reports of a conception and live birth following egg donation emerged in 1984 (Lutjen, 1984).
- ▶ This contributed to a worldwide demand for donor eggs, as more couples began to find the use of donated eggs acceptable (Purewal & van den Akker, 2009).
- ▶ However, it also led to widespread recognition that the demand for donor eggs far exceeds the supply, globally and in the United Kingdom (UK) (Human Fertilisation and Embryology Authority, (HFEA) 1998; Blyth & Frith, 2008).
- ▶ This imbalance has been especially acute in countries such as the UK, where overt payment to donors is prohibited. This led, in the UK, to the emergence of egg sharing schemes (Simons & Ahuja, 2005)



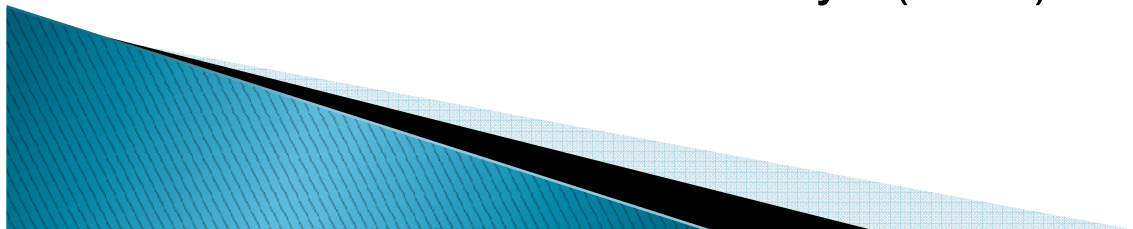
Defining egg sharing schemes

- ▶ Developed and promoted by Simons and Ahuja, as a 'self-help' scheme that enables qualifying women requiring assisted reproduction treatments (ARTs), the opportunity to access cheaper and in some cases, more expeditious treatment, if they agree to 'share' their eggs with up to two recipients (Ahuja & Simons, 1996; HFEA, 1996; Simons & Ahuja, 2005).
- ▶ However, the schemes have been criticised on moral, ethical and psychosocial grounds.
- ▶ It has also been suggested that criticisms "may be distinguished as either empirical or ethical concerns" (Blyth & Golding, 2008, p.467).



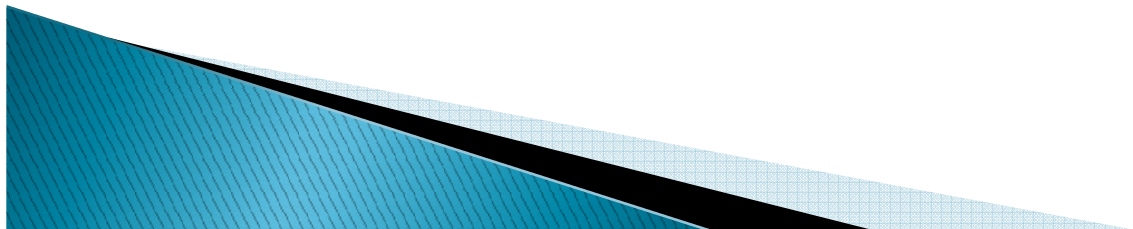
The study

- ▶ Sought to examine whether women can consent to share their eggs.
- ▶ This took into account any previous treatment utilised prior to them becoming an egg share donor.
- ▶ Data were collected from a self-selecting sample of egg share donors following a research request posted on the websites of Fertility Friends, Infertility Network UK and the National Gamete Donation Trust.
- ▶ E-mail interviews were conducted with four egg share donors. A further 13 egg share donors completed the online survey.
- ▶ E-mail interview data were analysed using the voice-centered relational method (VCRM) of analysis (Brown & Gilligan, 1990; Mauthner & Doucet, 1998; Gilligan et al., 2003; Martin, 2008).
- ▶ Survey data were analysed using the in-built functionalities of the Bristol Online Surveys (BOS) software package.



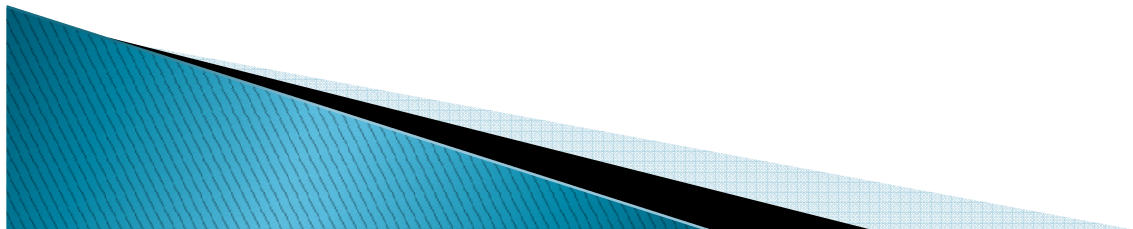
Provision of informed consent by egg share donors

- ▶ Data from the 17 participants involved in the study were used to assess the provision of informed consent.
- ▶ Survey respondents were asked:
 - ***Did you fully understand what you were giving consent to?***
 - Yes: 92.3%
 - No: 0.0% 0
 - Not really but didn't want to admit it: 7.7%
- ▶ Similarly, e-mail interview participants were asked about their understandings of the informed consent process.
- ▶ Significantly, each participant indicated that she understood what she was consenting to.

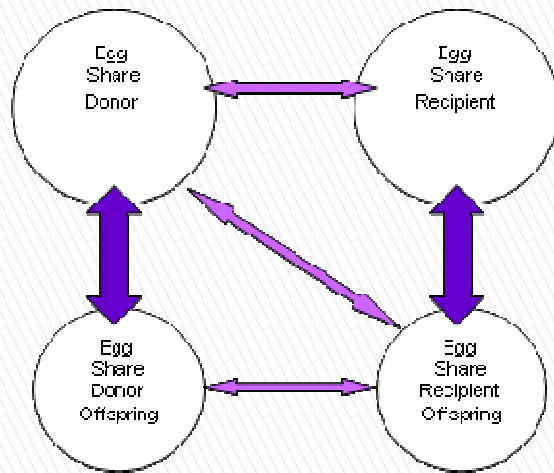


Post-treatment realities

- ▶ For example, Respondent 6 stated that:
 - *“It is a easy decision to make at the time, however in retrospect had any woman got pregnant it would have haunted me... In theory egg donation is a good idea, the reality however is very different, especially considering potentially another family could have the baby you want...”* (cited in Golding, 2011, p.162).
- ▶ Significantly, Florence stated that:
 - *“...you can't fully prepare yourself until it happens.”* (cited in Golding, 2011, p.245).



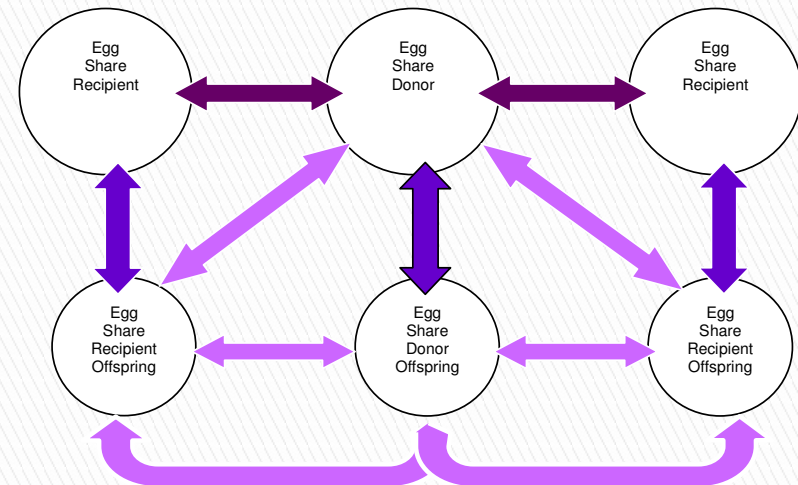
Revealing 'invisible' relationships



Key

- ↔ Denotes a visible relationship
- ↔ Denotes the creation of invisible interrelationships and interdependence

This diagram represents the 'invisible' relationships that emerge when one recipient is involved in the arrangement.



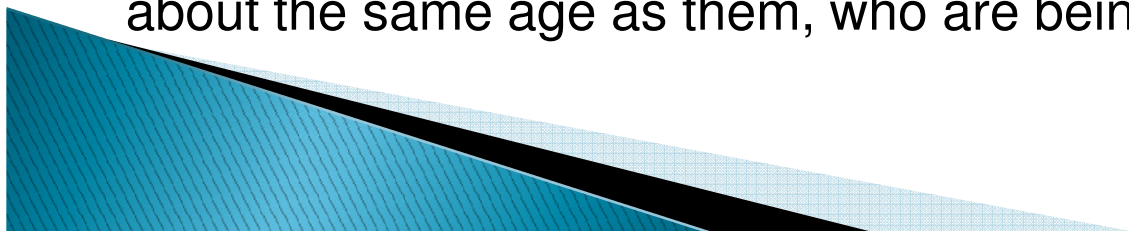
Key

- ↔ Denotes a visible relationship
- ↔ Denotes an invisible interrelationship
- ↔ Denotes the emergence of interdependence

This diagram represents the 'invisible' relationships that emerge when two recipients are involved in the arrangement.

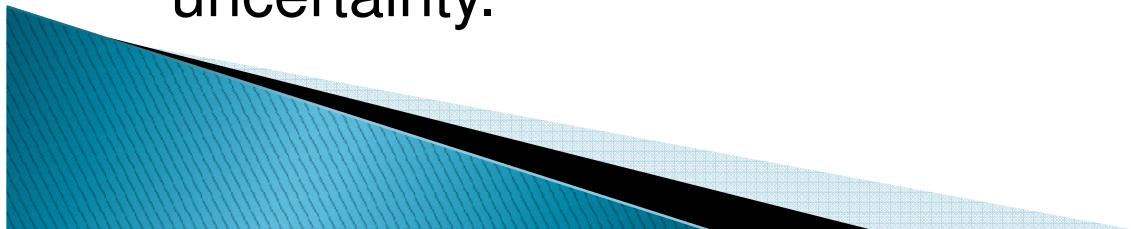
Potential future implications

- ▶ The interrelated aspects of egg sharing begins to change perceptions with regards to family formation and genetic relatedness.
- ▶ Thus, their awareness of the realities of their involvement in egg sharing become more apparent post-treatment.
 - Some donors have to contend with the knowledge that genetically related offspring who, in some cases are also half-siblings of her own child/children are growing up in other families.
 - They are also aware that these offspring may chose to contact them, if they are made aware of their conception, in the future when they reach the age of majority.
- ▶ What we do not currently know are the long-term implications of egg sharing for anyone involved and it will be some time before we do.
- ▶ Nor do we know how genetic offspring will regard the arrangement or their conception as a result of the donor's involvement.
- ▶ Similarly, we do not know how donor's own child/children will feel about the arrangement, or learning that they may have half-siblings who are about the same age as them, who are being raised in a different family.



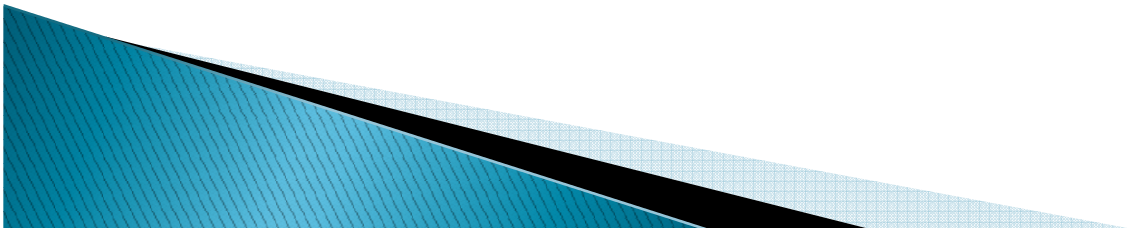
Conclusions

- ▶ To conclude, women can consent to share their eggs.
- ▶ The emergence of the post-treatment realities of egg sharing encompass issues related to genetic relatedness and the emergence of 'invisible' relationships.
- ▶ Egg sharing creates new family formations and importance needs to be attributed to the ensuing social, gestational, psychological, genetic, and familial roles.
- ▶ In some instances, egg share donors have to contend with the fact that they may encounter the 'knock on the door' scenario, when the child/children reach the age of majority.
- ▶ Some welcome this future outcome, while others express uncertainty.



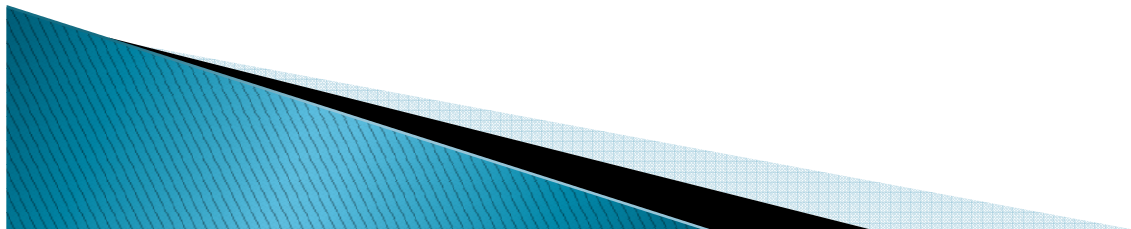
Thank you for listening.

Any questions?



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