



To say or not to say? Assisted reproductive technologies : Some challenges

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reproductive technologies : Some
challenges

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Assisted reproductive technologies (ARTs): some challenges

- Since its inception ARTs have generated different challenges.
Some examples are:
- From technical ones: no physical problems to the new borns;
- To societal ones: for example, until what age we should provide these technologies?

ARTs: some challenges

- A lot of debate has been focussed on the moral status of the embryo (the acceptance of production, criopreservation or destruction of embryos). Independently of the persistence of these discussions, ARTs are widely accepted and performed all around the world.

ARTs: some data

- Approximately 15 to 20% of couples have fertility problems. There is the assumption that ARTs are mainly performed in industrialized countries and to high and middle class couples.
- However in 2003, there were 186 million of couples in developing countries (excluding China).
- Centers practicing ARTs in Latin America: there were 263 to 300 fertility centers (IFFS (2007)).

ARTs: a current challenge

- There are other challenges that have not been so widely discussed but that nonetheless are very relevant. This lecture will focuss on this concern:
- **Should we maintain secrecy or disclose the origin of the gametes to the offspring when these techniques use a donor?**
- **How should we regulate ARTs regarding disclosure or anonymity?**

When does we may have to disclose?

- In very simple procedures (artificial insemination by donor (AID)). First reported case 1884 in France.
- To more complex ones: in vitro fertilization (1984 egg donor + in vitro), ICSI or in surrogacy arrangements. In these cases one of the gametes (sperm or eggs) can be given by a donor as well as the embryo.

Two steps procedure

- **Disclosure** implies telling the offspring about their donor conception origin;
- **Non-anonymity** implies revealing the identity of the donor.
- The donor can be: anonymous;
 - a known donor;
 - identifiable at a later stage in life (age 18).

Regulation

- The legislation is focussed on the second step: donor identifiability or not.
- Two models:
- Medical model (private arrangement with the physician/clinic: not necessary to disclose). Recall the first AID was in 1884.
- Adoption model (out of the medical realm-social work criteria). Children are raised in disclosure of their origin.

Similarities and (differences) with adoption

- No genetic link with (one or) both parents;
- ARTs children are born in the families in which they are raised (they are not relinquished by or removed from their biological parents) biological link is no major factor for psychological problems on children;
- However, there might be more challenges in identity formation in adolescence.
- **Adopted children are told, why ARTs with donor children are not?**

Arguments against disclosure

- 1. There is no secret, it is not an important issue.
- 2. To the general conviction secrets are a burden or bad for relationships, it is argued that secrets are not good or bad (it depends on circumstances).
- 3. Reproductive autonomy (personal standard evaluation based in their value system, life circumstances...).

To 1. and 2. Secrecy

- Family therapy literature explains secrets are detrimental to family functioning. They create boundaries between those who are party of the secrets and those who are not. (Golombok 2015)
- Children can sense information is withheld (tone of voice, body gesture, abruptly changing the subject, etc) (Papp,1993)

Secrecy

- These procedures are difficult to keep absolutely confidential with the couple (best friends, family....). Risks of «accidents».
- «It seems that open communication about donor conception and positive family functioning may go hand in hand.»
Golombok, S, 2015.

To 3. Comparative studies

- No conclusive and clear cut data... a bit of «dancing with data», difficult to measure.
- Quality of parenting of non-disclosing families found superior to natural families (Golombok et al, 1995).
- But mothers are more distressed (Wagner and Lane 2002).
- No data about adolescents.
- Gap between the intention to disclose and actual disclosure (Golombok 2000).

Reproductive freedom?

- There are no clear cut data....
- However, should reproductive freedom be absolute? Generally there are no absolute principles in bioethics... and what about the right of the child to know? What when they say they «need» to know?
- What kind of society are we promoting?

Functions of not telling

(Pennings, 2015)

- 1. Ensure that the man can fully commit himself as a father;
- 2. Protect the father as a father;
- 3. Promote the integration and recognition of the child in the broader family;
- 4. Protect the child against discrimination;
- 5. Respect the agreement between partners when non-disclosure was a condition.

Are these arguments valid arguments?

- A man that cannot commit as a father if it is known by his offspring there is not a biological link, seems not prepared for ARTs. Importance of promoting responsibility and accountability for our decisions.
- Protect the child from discrimination? Who has to know? Disclosure to the offspring is not equivalent to make the information public...

Changes: Non-traditional families

- Society has changed as well as families' structure (in the 70' less than 10% headed by single parents, around 30% in 2012 in USA and UK);
- Paralelled by the decline in marriage rates and the rise of divorces;
- 40% of all marriages are remarriages (UK)
- New families: gay, lesbian, solo, they have to tell and this challenges anonymity.

Changes: New mechanisms

- Australia (State of Victoria) donor-linking service is already in place.
- Countries with an open policy like Sweden since 1985 or the UK since 2005 provide the information if asked.
- Donor Sibling Registry (2000) is an internet site designed to facilitate search.
- «Open» sperm banks (option to disclose).



No imposition. An open possibility.

Other societal changes

- New patterns of communication and relation (influence of internet);
- Donors and families engaged in these techniques are searching links (creation of voluntary registries). Positive experiences. New kinship.
- Genetic era...in a relatively simple medical procedure it can be found out no linkage...

Some regulatory issues

- Who can have access and when?
- How to access? Importance of avoiding obstacles. Importance of adequate preparation.
- Relevance of the source of information. If private: safeguards to keep information safely for decades/ backups...
- Importance of keeping information private (careful regulation of documents)

Conclusion

- It seems the model from anonymity is rooted in the past, it does not consider the changes society has undergone and it does not consider the needs and rights of the offsprings.
- From an ethical point of view there seems to be a presumption in favor of disclosure with proper regulation regarding anonymity (though there might be a minority of justifiable exceptions).