Counselling in Gametedonation

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Aim of researchThe overall aim of this research is to contribute to a more adequate and congruent professional counselling of (intended) parents in the process of decision making on (non) disclosure of GD with their child.The specific aims are:1. to...

Ethical review	Approved WMO
Status	Pending
Health condition type	Family issues
Study type	Observational non invasive

Summary

ID

NL-OMON36284

Source
ToetsingOnline

Brief title
n.v.t.

Condition

- Family issues

Synonym
counselling, secrecy and disclosure in gametedonation

Research involving
Human

Sponsors and support

Primary sponsor: Academisch Medisch Centrum
Source(s) of monetary or material Support: Ministerie van OC&W

Intervention

Keyword: counselling, disclosure, gametedonation, secrecy

Outcome measures

Primary outcome

Not applicable. This is a qualitative research, so we try to identify

parameters.

Secondary outcome

Not applicable

Study description

Background summary

Non- anonymity and disclosure in gamete donation has been studied for years in recipients of Gamete Donation (GD). Comparative studies between parents who did and did not disclose GD show that parents who disclosed GD for their (non adolescent) children had a more positive parent-child relationship, less conflicts between them and their children, and better relationships between parents than in families where parents choose for secrecy. Nevertheless, families which kept GD secret, were functioning within the range of normal family life (Lalos et al., 2007; Paul & Berger, 2007).
According to Nagy, there is an essential loyalty between parents and children: he departs from the position that such an essential or *vertical* tie of loyalty with the biological origin is indissoluble and important for trust and self- esteem and though not always visible, it is always present (Böszörményi-Nagy, 1973). Therefore, biological origin is very important to be acknowledged and accepted (Böszörményi-Nagy, 1973, 1986; McGee et al., 2001).
Concealing important issues for a child by parents, or introducing another reality to avoid harm, may confuse children and disturb their psychological development (Dolto, 1971, 1984). Non disclosure of donor conception creates family tension because the secret is always present in the mind of the keepers and causes a troublesome burden with subsequent detrimental impact on the child (Daniels, 2009; McGee et al., 2001). For gamete donor offspring who discovered GD by coincidence and who are told later in life it is difficult to trust their parents, they have feelings of confusion, distress and anger, and feel a lack of genetic continuity (Daniels et al., 2007; Javda et al., 2009; Kirkman et al., 2007; Paul and Berger, 2007).
Past practice of anonymity and secrecy gradually changed in the direction of identified donors and disclosure, because of decreasing stigma of infertility, growing importance of children*s rights, increasing call of donor offspring for an end to secrecy, and legal changes (Akker, 2006; Daniels, 2006; McWhinnie,

2001). Apart from late disclosure and disclosure by accident, there is no evidence that disclosure is harmful for donor offspring (McWhinnie, 2001; Turner and Coyle, 2000). Disclosure appears to be important because of the need of trust and honesty within the family and acknowledgment of genetic continuity, attributes which are highly psychologically and socially valued (Turner and Coyle, 2001). Adult donor gamete offspring who have always known their origin feel good with a donor, feel loved by their family and have good relationships with their parents (Daniels et al., 2001, 2007; Paul and Berger, 2007; Scheib et al., 2005). Therefore, current tendency in literature is that parents using GD should tell their child of their true origin as early as a child can understand reproduction in general (Daniels, 2009; Javda et al., 2009; McGee et al., 2001; Landau, 2010). In practice single mothers and lesbian-couple families are more likely to disclose gamete donation and disclose from a younger age than heterosexual parents (Akker, 2006; Javda, 2009).
Since a few decades more (intended) parents opt for known gametes to have the possibility to respect the right of their child to know its origin (Akker 2006; Javda, 2009). Because of consensus about non anonymity and disclosure GD, several countries changed their laws. These countries don*t allow anonymity anymore and regulate provision of identifying information of donors to offspring (Daniels, 2007; Janssens, 2006; Wet Donorgegevens Kunstmatige Bevruchting Staatsblad, 2002).

Study objective

Aim of research
The overall aim of this research is to contribute to a more adequate and congruent professional counselling of (intended) parents in the process of decision making on (non) disclosure of GD with their child.
The specific aims are:
1. to explore the current counselling practices with regard to GD and to know on which (implicit) assumptions, cognitions and evidence these practices are based. 2. to get insight in when and how parents need assistance in the disclosing process about when and how to disclose GD to donor offspring.

Study design

Data will be collected by individual, semi structured in-depth interviews and focus groups.

Collection of data will take place in three groups of respondents:
- parents who told their child about the gamete donation
- parents who did not tell their child about the gamete donation
- professionals (doctors, nurses and non-medical social workers/ psychologists) involved in the counselling process of parents who use(d) gamete donation

Parents will be interviewed on individual basis.
Professionals will be interviewed first on individual basis, and later in focus groups.

Parents will be contacted by files of patients of several Centres for Reproductive Health in The Netherlands.

Professionals will be recruited from Dutch Centres of artificial reproduction.
Interviews will be held by topic lists, which will be based on literature and professional experiences of the research team. The focus groups will be held by topic lists and results of the interviews.

All interviews will be audio recorded and transcribed ad verbatim.

Study burden and risks

The effort for participants is a visit to the researcher for the interview.
When desired the researcher will interview a participant in his own place.
Participants will be interviewed on individual basis. The interviews are semi structured depth-interviews that will be held by topic lists. Next to it, focusgroups will be held with professionals, also by topiclists en based on results of interviews.

Psychological inconvenience is not expected, though is realized an interview could effect someone. In the patient information letter participants can read what the research is about, but when their experience about the effect will be different after the interview and they need support, a professional counsellor is available. Participation is on fully voluntarily basis. Participants are not denied any treatment when they don't participate.
By participation respondents get attention for their (specific) situation (namely it was possible to get a family by using GD), they can give their opinion upon their situation and with their experiece they can contribute to increase professional counselling in case of GD. This can outweigh the emotional inconvenience participation could give. The possibilily of professional counselling that is offered seems to be justified and sufficient.
Because respondents are asked to participate by asking fertility centres, where respondents have been treated, to cooperate can give them the acknowledgement that this clinics are interested in their situation and experiences.

Psychological inconvenience for professionals is not expected.

Contacts

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Trial sites

Listed location countries

Netherlands

Eligibility criteria

Age
Adults (18-64 years)
Elderly (65 years and older)

Inclusion criteria

- parents who told their child about the gamete donation
- parents who did not tell their child about the gamete donation

Exclusion criteria

parents who did not use gematedonation

Study design

Design

Study type: Observational non invasive

Masking:	Open (masking not used)
Control:	Uncontrolled
Primary purpose:	Other

Recruitment

NL

Recruitment status:	Pending
Start date (anticipated):	01-04-2011
Enrollment:	30
Type:	Anticipated

Ethics review

Approved WMO

Application type:	First submission
Review commission:	METC Amsterdam UMC

Study registrations

Followed up by the following (possibly more current) registration

No registrations found.

Other (possibly less up-to-date) registrations in this register

No registrations found.

In other registers

Register	**ID**
CCMO	NL34654.018.11