

Psychosocial guidance and counselling of intended parents, donor-children and sperm donors on Sperm Donation (SD)

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Objective of the studyThe aim of this study is to optimize the education, psychosocial counselling and guidance for (intended) parents, children conceived by means of DST and the sperm donors. It is the intention that with the findings of the...

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

Summary

ID

NL-OMON42423

Source

ToetsingOnline

Brief title

Guidance and counselling on SD

Condition

- Family issues

Synonym

Begeleiding en counseling

Research involving

Human

Sponsors and support

Primary sponsor: Academisch Medisch Centrum

Source(s) of monetary or material Support: ZonMW

Intervention

Keyword: Counselling, Guidance, Sperm donation, Well-being

Outcome measures

Primary outcome

Primary research variables / outcomes

The qualitative part:

Not applicable. It is a qualitative study, so we try to identify parameters.

The quantitative part:

a) Unmet Needs for Support: To identify which questions (intended) parents, offspring (16 years and above) and donors have on all kinds of domains that are related to DST, to what extent they experience DST as stressful and to what extent these needs are unfulfilled we will use the format of Structured Problem Analysis of Raising Kids (SPARK; Dutch translation of Vragenlijst Onvervulde Behoeften aan Opvoedingsondersteuning, VOBO; Bertrand et al.,1998). The SPARK format consists of a standardized structure in which the participant first are asked what kind of problems they had experienced during the last 12 months, followed by the question how stressful these problems were and whether one did receive guidance to deal with these problems and if so, what the content of this guidance and how helpful it was. Because of the sequential demand structure questions will only be asked if that is needed. When participants did

not experience any problem, completing this instrument will take only a few minutes. The original SPARK will be adapted for this study to: 1) the different groups of participants ((intended) parents, children ages 16 and older and donors) and 2) the subject of DST. The original items of the SPARK will be replaced by domains addressing questions (intended) parents, children and donors can have regarding to DST. These domains are determined on the basis of the literature and as emerged from the qualitative part of the study (see the above description of the qualitative part). A separate version of this questionnaire will be developed for each target group (intended) parents, children (only for those who know that they were conceived by means of DST) and donors.

b) Psychosocial well-being: The psychosocial wellbeing (desire) parents and donors is will be measured by the Adult Self-Report (ASR; Achenbach & Rescorla, 2003). Parents will be also asked to complete the Child Behavior Checklist on their children (CBCL; Achenbach & Rescorla, 2000). Children aged 16-18 will be asked to fill in the Youth Self-Report (for children up to 18 years old (Achenbach & Rescorla, 1991), older children also will asked to complete the ASR.

c) Emotional involvement and concern parents: The extent to which parents are emotionally involved in rearing their child and are concerned about childrearing and their child's development will be on the basis of the Dutch translation of the Child Rearing Practices Report (CRPR; Block, 1965).

d) Childrearing related stress: Childrearing-related stress will be assessed by three subscales from the Childrearing stress questionnaire (in Dutch: Opvoedingsbelastingvragenlijst - OBVL; Vermulst, Kroes De Meyer, Nguyen, & Veerman, 2012): (1) difficulties in the parent-child relationship, (2) difficulties related to rearing the child, and (3) role limitations.

e) Partner relationship of the (intended) parents: To investigate the couple relationship in heterosexual and lesbian couples we will use two instruments. First we will use the *general relationship satisfaction questionnaire* (Gerris et al., 1993; Wood et al, 2004, 2007) to measure general relationship satisfaction. Secondly, we will assess the satisfaction of the partner as co-parent and for this we will use a subscale of *the Parental Stress Index* (Abidin, 1983; Groenendaal et al., 1996; zie ook Bos et al., 2004, 2007).

f) Socio-demographic data (intended) parents, children and donors: The following socio-demographic background data is queried: age, biological sex (assigned at birth), level of education, cultural background, family type (in (intended) parents and children), age of child(ren), type of donor, infertility history of the (intended) parents.

Secondary outcome

not applicable

Study description

Background summary

Background of the study

Donor Sperm Treatment (DST) is a widely used fertility treatment. In the Netherlands, more than 1,000 women trying to get pregnant by means of DST are starting annually. In the course of time the societal discourse surrounding DST changed with consequences for both psychosocial screening and counselling and guidance of (intended) parents and donors. In the 70s, for example, it was recommended to be strictly secret about the genetic origin of the donor-offspring although there was no empirical evidence for this non-disclosure. Since the 80s there was a shift towards an approach in which openness was advocated, and in this sense one followed the advice of the Human Rights Council.

Psychosocial counselling and guidance for couples (heterosexual or lesbian) or singles with the focus on awareness of the implications of starting a family with semen from a third party, is strongly recommended in international guidelines (Ethics Committee ASRM, 2013; HFEA, 2013; Greenfeld, 2008; McWhinnie, 2001; Nice, 2013). Dutch professionals (gynecologists, nurses, embryologists and counsellors) who are involved in DST, also emphasize the importance of this psychosocial counselling, but they have to rely on a lack of scientific knowledge about this content and the need for psychosocial counselling and guidance of the (intended) parents, donor-children and donors (Visser et al., 2012). The focus of the present study is on the needs of (intended) parents, children conceived by means of DST and sperm donors and it will be investigated what topics should be included in the abovementioned psychosocial counselling and guidance.

Study objective

Objective of the study

The aim of this study is to optimize the education, psychosocial counselling and guidance for (intended) parents, children conceived by means of DST and the sperm donors. It is the intention that with the findings of the present study we can develop in the future quality based standards and guidelines for education, psychosocial counselling and guidance regarding to DST. The results of the study will also provide information based on which in the future it is possible to develop methods, interventions and guidelines for psychosocial counseling and guidance for individuals dealing with oocyte donation.

Study design

Research design

The study consists of two parts: a qualitative and a quantitative part.

A)

In the qualitative part, data will be gathered by means of individual, semi-structured in-depth interviews with (intended) parents, children aged 16 and older and donors. The interviews with the parents and donors have already taken place and the Medical Ethical Committee (METC) of the AMC did approved this part of the study (see Project: METC 10/302; submitted by Drs M. Visser). The interviews with the intended parents and children (16 years and older) have yet to take place and with this request we are asking the METC for permission to start with this part.

The interviews will be held on the basis of a *topic list*, which will be based on the literature and professional experience of the research team. All interviews will be tape-recorded and ad verbatim be issued.

Intended parents will be recruited in two ways:

- 1) by announcements on Facebook, Twitter and the website of patient association Freya. Intended parents who will respond on this announcement will get a patient information letter with the objectives of the qualitative research.
- 2) the Centre for Reproductive Medicine (CRM) of the AMC and MCK Fertility Centre will inform their patients who want to make us of sperm donation.

The offspring who were conceived by means of DST and who are 16 year or older also will be contacted in several ways:

- through *Stichting Donor Kind* (association for offspring conceived by means of DST)
- via Fiom
- through announcements on social media, websites, forums
- through Centre for Reproductive Medicine (AMC) and MCK Fertility Center: they will contact the parents of the offspring conceived by means of sperm donation; this because there might be children who do not know that they are conceived by means of DST and we want to avoid that the disclosure will be forced through our letter. Children will be contacted by the parents and the consent of the parents.

The interviews will also be included children who have already had contact with their donor.

B)

The quantitative part consists of a digital questionnaire on a protective website (there will be also a pencil-paper version available for participants who prefer to fill out the questionnaire in this way). This questionnaire will be administered to a larger group of participants consisting of (intended) parents, offspring (older than 16 years old) conceived by means of DST and

sperm donors. This with the aim to explore what needs for guidance, information and counselling they have and which of these needs are unfulfilled. The items for the questionnaire (prepared according to the format of the VOBO- see below) used in the quantitative part, will be based on the findings from the semi-structured interviews (qualitative part). In the quantitative part we will also investigate the associations between the unmet needs for guidance regarding issues related to DST and the daily functioning of (intended) parents, the offspring (16 years and older) and donors (emotional involvement and concern, childrearing-related stress, partner relationship, psychosocial well-being of the (intended) parent / offspring / donor) and to the association with socio-demographic background characteristics, family type and type of donor, age of the offspring, and openness about sperm donation.

Participants ((intended) parents, offspring 16 years and older, and donors) for the quantitative part are also recruited through social media (Facebook and Twitter), via websites and forums (including Freya St. Donor Child, Fiom) and via the Centre for Reproductive Medicine (AMC) and MCK Fertility Center. In addition, participants who indicated that they want to be involved in the qualitative part are informed about this part of the study and asked to participate.

Study burden and risks

Nature and extent of the burden and risks associated with participation, benefit and group relatedness

The qualitative part:

The effort for the participants (target research groups: a. (intended) parents and children older than 16 years old) is taking part in an interview of 1 to 1,5 hours. The estimate of the duration of an interview is based on the earlier interviews with parents and donors (which METC has approved; see Project METC: 10/302). An interview may take place at home of the participant or at the University of Amsterdam (depending on the choice of the participant).

Psychological inconvenience is not expected; although we realize that the interview can be confronting and might effecting someone. In the Patient Information Folder (PIF) potential participants can read where the research is about, but when their experiences about the effect are different than what we expect, participants can get support from a professional counselor (contact details are given). In the PIF it will make clear to the intended parents that not willing to take part of the study will not influence their (medical) treatment at the Centre for Reproductive Medicine (AMC) and MCK Fertility Center.

It is expected that by taking part in the study participants will receive attention to their (specific) situation and that they can express their

experiences. With their experience they can contribute to the further professionalism of psychosocial guidance and counselling of (intended) parents, children and donor sperm donors by DST. This may outweigh the emotional inconvenience participation in the study could give. The professional guidance that is offered seems to be justified and sufficient.

The quantitative part

It is estimated that completing the online questionnaire (whose data are stored on a secure server) takes between 30 to 40 minutes. Potential respondents will be drawn to the estimate duration of completing the online questionnaire in the PIF.

Also for the quantitative part we do expected that taking part will be psychological inconvenient for the participants. The PIF will indicate where the research is about and that when they want participants can get support from a professional counselor (contact details are given) after they have complete the questionnaire. This information (including the contact information of the professional counsellor) will also be once more at the end of online survey.

In the PIF for the intended parents it will be clearly stated that treatment will not withheld if they are not willing to take part at our study.

Also in this part of the research it is expected that respondents will receive attention to their (specific) situation and that they can reflect on their needs for guidance and possible background of their needs.

Contacts

Public

Academisch Medisch Centrum

Meibergdreef 9 Meibergdreef 9
Amsterdam 1105 AZ
NL

Scientific

Academisch Medisch Centrum

Meibergdreef 9 Meibergdreef 9
Amsterdam 1105 AZ
NL

Trial sites

Listed location countries

Netherlands

Eligibility criteria

Age

Adolescents (12-15 years)

Adolescents (16-17 years)

Adults (18-64 years)

Elderly (65 years and older)

Inclusion criteria

For qualitative part:

- intended parents who want to use donor sperm treatment (DST)
- donor-offspring aged 16 and older (and who know they are conceived by DST)

For quantitative part:

- intended parents who want to use DST
- parents who conceived by using DST
- donor-offspring aged 16 and older (and who know they are conceived by DST)
- sperm donors

Exclusion criteria

- (intended) parents, donor-offspring not using DST or born after DST
- men who did not donate sperm for DST

Study design

Design

Study type: Observational non invasive

Masking: Open (masking not used)

Control: Uncontrolled

Primary purpose: Other

Recruitment

NL
Recruitment status: Completed
Start date (anticipated): 03-10-2015
Enrollment: 140
Type: Actual

Ethics review

Approved WMO
Date: 09-09-2015
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

ID: 20189
Source: Nationaal Trial Register
Title:

In other registers

Register	ID
CCMO	NL53349.018.15
OMON	NL-OMON20189