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Counselling on disclosure of gamete donation to donor offspring: a search for facts

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Abstract

Background: High quality counseling of potential parents is needed in the process of disclosure to donor offspring, which is important for the child and for family relationships. We performed a search for facts to identify the role of counseling in couples undergoing gamete donation.

Methods: We systematically searched Pubmed, EMBASE and Psycinfo. Studies were included if they reported on counseling in gamete donation.

Results: A total of 20 studies were included. Twelve studies stated that counselling was offered. The reported studies reflected no consensus about when and how counselling in gamete donation should be offered and no theoretical background of the disclosure/ secrecy issue. About 50% of the parents expressed the need for guidance and support of a counsellor. Special concerns were the disclosure issue and the future contact with the donor. Parents did not receive the guidance and support they needed in the disclosure process after treatment.

Conclusion: Empirical knowledge on counselling is lacking. This review demonstrates the need to know more precisely at what moments couples should be counselled, and which specific information and guidelines couples need to receive to be more confident in the disclosure process to donor offspring.

Key words: Counselling, gamete donation, secrecy, disclosure, donor offspring, family relationships.

Introduction

In the treatment of couples with gamete donation assistance of a professional counsellor is essential to thoroughly examine the many dilemma's faced by these couples (Greenfeld, 2008; McWhinnie, 2001). Through counselling couples can be fully informed about the unique psychosocial aspects of gamete donation and aided in seeing donor insemination from the point of view of their child (Hammarberg et al., 2008). The Ethics Committee of the ASRM states it is essential that couples are counselled and sign an informed consent about disclosure (Ethics

Committee of the American Society for Reproductive Medicine, 2003).

In addition to counselling to prepare couples for gamete donation, post donation guidance seems also to be important, because after birth parents experience disclosure differently from before (Baetens et al., 2000; Kirkman 2003; van den Akker 2006; Daniels et al., 2009). HFEA guidelines (United Kingdom) set out different types of counselling that should be available in gamete donation: counselling to understand the implications of the treatment for the couples themselves, their family and their child, counselling for emotional support and counselling

to help couples to cope with the consequences of infertility and treatment (Human Fertilization and Embryology Act, 1990).

Typical for counselling in gamete donation is the issue of disclosure. Several institutes in the field of Assisted Reproductive Techniques (ART) like the Human Fertilisation and Embryology Authority (HFEA), and the American Society of Reproductive Medicine (ASRM), as well as The United Nations Convention of the Rights of the Child (UNCRC) offer guidelines that encourage disclosure to donor offspring and respect the rights of the child (Human Fertilization and Embryology Act, 1990; Ethics Committee of the American Society for Reproductive Medicine, 2004). The importance of these guidelines is underpinned by legislation in several European countries, New Zealand and some states of Australia, giving donor offspring the right to know their donor's identity at the age of 16 or 18 (Janssens et al., 2005; Daniels et al., 2009). Comparative studies between parents who did and did not disclose gamete donation show that parents who disclosed gamete donation 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 gamete donation secret, were functioning within the range of normal family life (Lalos et al., 2007; Paul and Berger, 2007). 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 (McGee et al., 2001; Daniels, 2009). The biological origin is very important to be acknowledged and accepted, because it gives trust and self-esteem to donor offspring (McGee et al., 2001).

However, it is known that without having received the proper information on the disclosure issue, many couples tend to do nothing, even though it may be in their own and child's best interest (Baran and Pannor, 1993). Studies on gamete donor recipients and donor offspring have shown that parents often want or intend to disclose, but are afraid of the consequences. Moreover, parents are uncertain about the timing and about how to present information of the donation. They especially fear that disclosure could have a negative effect on the parent-child relationship and therefore tend to postpone disclosure to donor offspring (Gottlieb et al., 2000; Söderström et al., 2010; van den Akker, 2006; Hershberger et al., 2007; Daniels et al., 2011). In case parents intend to disclose gamete donation to their child, but do not do so, the child seems to have no rights while laws have changed. More specific research is needed to

know how to support parents to bridge the discord between parents cognition and behaviour and in favour of the children's rights (van den Akker, 2006). These data reinforce the need for proper and high quality professional counselling in preparing parents for disclosure and other aspects related to family building based on donor gametes.

In this review we provide an overview of available facts and data about the need for counselling and the content of counselling for couples undergoing gamete donation on the one hand, and the role of the counsellor with regard to disclosure on the other hand.

The quality of the different studies varied a lot. Only two studies used validated scales to analyze the questionnaires (Hahn and Craft-Rosenberg, 2002; Hammarberg et al., 2008). Moreover some studies entailed a very small population of women, which makes the data hard to interpret (Salter-Ling et al., 2001; Murray and Golombok, 2003; Hershberger et al., 2007; Lalos et al., 2007).

Also, eight studies did not describe if counselling was performed (Lindblad et al., 2000; Muray and Golombok, 2003; Hershberger et al., 2007; Lalos et al., 2007; MacDougal et al., 2007; Grace et al., 2008; Daniels et al., 2009; Söderström et al., 2010), which makes the quality assessment of these articles difficult in relation to disclosure.

In twelve of the 20 studies we found that counselling was offered, but very little on how couples were counselled. In one study tools for parents to disclose to donor offspring were described like: in the presence of both parents, in an early point in life, for instance when a child asks about conception in general and according to the developmental level of the child, though it is not mentioned on which evidence these tools are based. The moment when counselling was offered was not clear in 6 of these twelve studies.

Material and methods

Search strategy and study selection

We performed a structured literature search using Pubmed, EMBASE and Psychinfo from incipience to March 2012. An information specialist (JD) performed a systematic search using the following search strings:

Search strings for medline:

("donor offspring"[tiab] OR donation OR insemination) AND (confidentiality OR secrets OR secrecy OR disclosure OR anonymity OR "right to know" OR revelation OR openness) ("donor offspring"[tiab] OR donation OR insemination) AND (confidentiality OR secrets OR secrecy OR disclosure OR

anonymity OR “right to know” OR revelation OR openness) AND (counselling)

Search strings for EMBASE:

((gamete donation OR donor offspring OR donation OR insemination).mp) AND ((exp parental attitudes/ OR (confidentially OR secret OR secrecy OR disclosure OR anonymity OR right to know OR revelation OR openness).mp)

Search strings for PsychInfo:

1. (fertility counselling OR (counselling and fertility)).tw.
2. ((gamete donation OR donor offspring OR donation OR insemination).tw) AND (exp parental attitudes/ OR (confidentially OR secret OR secrecy OR disclosure OR anonymity OR right to know OR revelation OR openness).tw.)

We followed the Prisma guidelines.

Inclusion and exclusion criteria

Articles were included if they reported on (1) counselling in gamete donation and (2) decision making of parents in gamete donation. We only included empirical studies and excluded editorials or articles on ethical subjects. Studies on both heterosexual and homosexual couples were included in the search, though only studies on heterosexual couples were found. This review is focussed on couples with one genetic parent. Data on embryo donation were excluded, because in these cases neither of the parents have a genetic link with the child.

Identification

The abstracts of all the articles identified through the search were read by two researchers (M.V., P.K.). If there were any doubts about eligibility after reading the abstract, they screened the full text to make sure no papers were missed. In case of disagreement, the decision of a third reviewer (M.W.) was final.

Methods of review

From each included article the following data were extracted: study characteristics specified as randomized study or not- randomized study, prospective or retrospective cohort study, inclusion and exclusion criteria, number of participants, number of families, sampling strategy, percentage of disclosure, if counselling was performed and finally which topics and decisions were important for parents in the disclosure process.

Results

Results of search

The search retrieved 845 articles from Pubmed, EMBASE and Psychinfo. The process of article selection is summarized in Fig. 1. After screening titles and abstracts 53 articles were selected for further reading. 33 papers did not meet the inclusion criteria, because they did not report on counselling (van den Akker, 2006; Araya, 2011; Broderick et al., 1995; Broderick et al., 2001; Cook et al., 1995; Crawshaw, 2002; Daniels et al., 2001; Daniels et al., 2011; Dresser, 2001; Feast, 2003; Gottlieb et al., 2000; Greenfeld, 2008; Hershberger et al., 2004; Lampic et al., 2009; Landau et al., 2003; Leeb-Lundberg et al., 2006; Leiblum et al., 1992; Lycett et al., 2004; Mahlstedt et al., 1998; McGee et al., 2001; McWhinnie, 2000; Meijer et al., 1980; Milsom, 1982; Pike S, 2005; Purewal et al., 2009; Rowland, 1985; Jadva et al., 2009; Jadva et al., 2011; Readings et al., 2011; Smith, 1979; Spring, 1974; Svanberg et al., 2008; Yee et al., 2011).

A total of 20 articles, reporting on counselling and prospective parents' decision-making in disclosure in gamete donation were included in the review. Two articles reported on the same population; both were included as they present different outcomes (Grace et al., 2008; Daniels et al., 2009). Two other articles also reported on the same population; both were included, because they also presented different outcomes (MacDougall et al., 2007; Shehab et al., 2008).

Characteristics of included studies

The included 20 studies were performed in European countries (the UK, Sweden, Belgium, Finland), in the USA, New Zealand and Australia. The study characteristics including the key features on samples, methodologies and aims of research of the studies are summarized in Table I. No randomized studies were found. Of the 20 studies, two were prospective and the other 18 were retrospective studies.

Characteristics of the study population

The 20 studies were performed in 2151 couples that were all heterosexual. For 2126 couples both female and male partners participated, for 25 couples only the women were invited to participate (Murray and Golombok, 2003; Hershberger et al., 2007). The gamete donation concerned donor insemination (DI) in ten studies, oocyte donation in six studies and a combination of oocyte and donor insemination in another four studies. The number of participants in

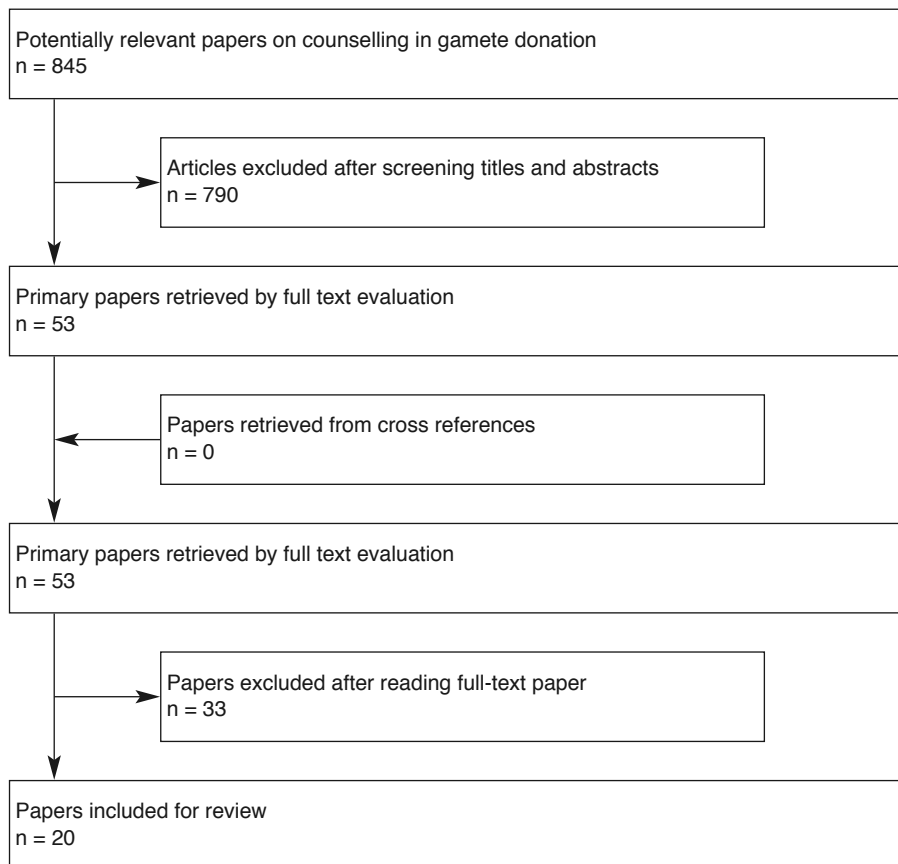


Fig. 1. — Process from initial search to final inclusion for papers on counselling and parental concerns in disclosure in gamete donation.

these studies varied between 8 and 267 couples (Table I).

Characteristics of methodology

Information was retrieved by questionnaires in nine studies (Durna et al., 1997; Hahn and Caft-Rosenberg, 2002; Hammarberg et al., 2008; Isaksson et al., 2011; Leiblum and Avis, 1997; Lindblad et al., 2000; Nachtigall et al., 1998; Salter-Ling et al., 2001; Söderström et al., 2010), in one study by telephone interview after a questionnaire (Rumball and Adair, 2003), in one study by telephone interview (Lalos et al., 2007) and by face-to-face interviews in nine studies (Baetens et al., 2000; Daniels et al., 1995, 2009; Grace et al., 2008; Hershberger et al., 2007; Laruelle et al., 2011; MacDougall et al., 2007; Murray and Golombok, 2003; Shehab et al., 2008). In the nine studies wherein couples were approached by questionnaire, all couples received separately the questionnaire. In four other studies partners were interviewed separately (MacDougall et al., 2007; Baetens et al., 2000; Lalos et al., 2007; Rumball and Adair, 1999). In two of the other studies both partners were interviewed together (Daniels et al., 1995; Laruelle et al., 2011); in one study partners

were interviewed together and separately (Shehab et al., 2008); in two studies couples were interviewed together, but in case of divorce couples were interviewed separately (Daniels et al., 2009; Grace et al., 2008) and in two studies the male partner was not interviewed (Hershberger et al., 2007; Murray and Golombok, 2003) (Table I).

Characteristics of the counselling process

Study findings about counselling are provided in Table II. Of the twenty included studies, twelve studies explicitly stated that couples received counselling (Baetens et al., 2000; Daniels et al., 2009; Durna et al., 1997; Hahn and Caft-Rosenberg, 2002; Hammarberg et al., 2008; Isaksson et al., 2011; Laruelle et al., 2011; Leiblum et al., 1997; Nachtigall et al., 1998; Rumball and Adair, 1999; Salter-Ling et al., 2001; Shehab et al., 2008). Nine of these twelve studies reported about the actual number of couples that underwent counselling before or after gamete donation. In six of these studies all couples received counselling (Baetens et al., 2000; Daniels et al., 2009; Hahn and Caft-Rosenberg, 2002; Hammarberg et al., 2008; Laruelle et al., 2011; Salter-Ling et al., 2001). In the other three studies respectively 33%, 94% and

Table I: Characteristics of studies (OD = oocyte donation, GD = gamete donation, DI = donor insemination).

Author (year) country	Sample	Method and design	Aim of Research
Daniels et al. (1995) New Zealand	58 couples, donor insemination	Retrospective study/ interview	Examine the nature of agreement and the dynamics between parents to disclose
Leiblum et al. (1997) USA	27 couples, donor insemination	Retrospective study/ pilot tested questionnaire, with 1-6 point scale	Examine how couples deal with disclosure after donor insemination; discrepancy between men and women
Durna et al. (1997) Australia	267 couples, donor insemination	Retrospective study/ questionnaire	Examine attitudes of parents of disclosure to their child after donor insemination
Nachtigall et al. (1998) USA	184 couples, donor insemination	Retrospective study/ questionnaire	Examine disclosure decision after donor insemination and identify concerns and issues that influence parents disclosure decision
Rumball et al. (1999) New Zealand	78 couples, donor insemination	Retrospective study/ questionnaire after telephone interview, multiple choice and open ended.	Examine experiences of disclosure and intention to disclose, and donor offspring responses
Lindblad et al. (2000) Sweden	148 couples, donor insemination	Retrospective study/ questionnaire	Examine reasons why couples do or do not disclose donor insemination to their child; reasons that influence decision making after donor insemination
Baetens et al. (2000) Belgium	144 couples, oocyte donation	Retrospective study/ Interview	Analyse decision making process, and influence of counselling. Donors' motivation in case of personal relationship with the acceptant(s).
Salter-Ling et al. (2001) UK	24 couples, donor insemination, included 11 network group couples	Retrospective study/ questionnaire	Examine levels of distress and concerns, and the role of counselling. Explore views of couples about disclosure to donor offspring
Hahn et al. (2002) USA	31 couples oocyte donation	Retrospective study/ questionnaire, 15 open-ended and 6 closed questions. Scales: (FES), (SS-A)	Identify variables influencing disclosure decisions, plus effect on families
Murray et al. (2003) UK	17 couples, oocyte donation	Retrospective study/ interview	Examine the extend of openness, decision-making factors on whether, what and how to disclose to their child in oocyte donation
MacDougall et al. (2007) USA	141 couples, gamete donation (62 DI, 79 OD)	Retrospective study/ interview	Examine how parents envision, plan and enact disclosure after gamete donation to donor offspring
Hershberger et al. (2007) USA	8 women, oocyte donation	Retrospective study, qualitative naturalistic/ 2 interviews 9-23 weeks after gestation	Provide in- depth descriptions of disclosure experience, and influencing factors for disclosure

Lalos et al. (2007) Sweden	19 couples, donor insemination	Retrospective study/ telephone interview (<i>follow up study</i>)	Examine parents' thoughts about openness and whether, when and how to disclose donor insemination to their child and examine experiences with health care professionals
Hammarberg et al. (2008) Australia	184 couples, gamete donation	Retrospective study/ self reported questionnaire T1-T2, 7 point Lickert scales	Examine donors and recipients views about counselling, beliefs about disclosure before and after counselling
Grace et al. (2008) New Zealand	41 couples, donor insemination	Retrospective study/ interview	Examine parental thinking about donated gametes and the role of the donor in building family
Shah et al. (2008) USA	141 couples gamete donation (62 DI, 79 OD)	Retrospective study/ In-depth interview	Analyze the decision-making process in couples after donor insemination
Daniels et al. (2009) New Zealand	43 couples, donor insemination	Retrospective study/ interview in <i>follow up study</i> . Counselling T1: doctors, T2 trained professional counsellors	Examine parental decision-making regarding information sharing with donor offspring after donor insemination
Söderström et al. (2010) Finland	167 couples, oocyte donation	Retrospective study/ questionnaire	Examine parents' plans of disclosure to their child and others, their attitude and satisfaction after oocyte donation
Isaksson et al. (2011) Sweden	257 couples, gamete donation (127 DI, 152 OD)	Prospective study/ questionnaire T1 before treatment, T2 after start treatment. Control group: sperm recipients	Investigate couples attitudes towards disclosure to their child and genetic parenthood, disclosure behaviour to others, and need of information and support regarding parenthood after gamete donation
Laruelle et al. (2011) Belgium	135 couples, oocyte donation and 90 donors	Prospective study/ semi structured interviews	Compare motivations, choices and attitudes of recipient couples in 3 types of donations in oocyte donation and assess donors motivations.

56% of the couples received counselling (Leiblum et al., 1997; Rumball and Adair, 1999; Shehab et al., 2008). In eight studies it seemed that couples had been counselled, but this was not explicitly mentioned (Daniels et al., 1995; Grace et al., 2008; Hersberger et al., 2007; Lalos et al., 2007; Lindblad et al., 2000; MacDougall, 2007; Murray and Golombok, 2003; Söderström et al., 2010).

The information provided about the counselling practices in the different clinics (counselling being voluntary or mandatory, for whom counselling was available and what type of counselling was offered) was limited and varied substantially among the various studies. Still, the limited information showed considerable differences in counselling practices. In four studies counselling was available (Baetens et

al., 2000; Daniels et al., 2009; Hahn et al., 2002; Hammarberg et al., 2008). In two studies it was explicitly mentioned that counselling was available, but not mandatory (Nachtigall et al., 1998; Shehab et al., 2008). In three studies it was mentioned that counselling was mandatory for certain cases or on specific moments. In one study with sperm and oocyte donation couples, many sperm donor couples did not, but most oocyte donation couples did receive counselling that was mandatory or they received voluntary counselling at specific decision points (Shehab et al., 2008). In one study couples received mandatory 'implication counselling' before treatment to consider the implications of the treatment for themselves, their families and any potential child (Salter-Ling et al., 2001). In another study cou-

Table II. — Disclosure and counselling.

Author (year) country	Disclosure to donor offspring	Intended to disclose before conception	Age donor offspring at time of disclosure	Counselling wanted; for what reasons	Received counselling
Daniels et al (1995) New Zealand	unknown	unknown	unknown	not clear	uncertain
Rumball et al. (1999) New Zealand	30%, (34% < 3y; 30% < 2y; 20% < birth)	majority	0-8 y	-----	yes, 94%
Grace (2008) New Zealand	34%	19%	unknown	not clear	uncertain
Daniels et al. (2009) New Zealand	35%	18%	unknown	5 couples asked for 2nd counselling later by professional counsellor	yes, 100%
Durna et al. (1997) Australia	5%	18% intend before conception 45% did	0-15 y, mean age disclosure 6,3 y	not clear	Yes
Hammarberg et al. (2008) Australia	84%	unknown	unknown	75%	yes, 100%
Leiblum et al. (1997) USA	25%	unknown	1-13y	not clear	yes, 33%
Nachtigall (1998) USA	30%	unknown	unknown	not clear	yes, not mandatory
Hahn et al. (2002) USA	39%	unknown	6 month- 5y	35%	yes, 100%
Hershberger et al. (2007) USA	0%	50%	before birth	not clear	uncertain
MacDougall et al. (2007) USA	32% DI mean age 7,2 23% OD, mean age 3,6	48% DI 58% OD	uncertain	not clear	unknown
Sehab et al. (2008) USA	32% DI, mean age 7,2; 23% OD, mean age 3,6	28% DI, 58% OD	unknown	not clear	yes, for DI not mandatory. For OD mandatory and many
Lindblad et al. (2000) Sweden	11%	41%	0-12	not clear	uncertain
Lalos et al. (2007) Sweden	61%, 3,5- 5 y	33%	1-10 y	not clear	uncertain
Isaksson et al. (2011) Sweden	0%	90%	before birth	33% wanted more information (26% of men, 40% of women), 7% did not receive any information	yes, by psychosocial work before treatment
Baetens et al. (2000)/ Belgium	33%	44%	unknown	-----	yes, 100%
Salter-Ling et al. (2001) UK	unknown	100% (network group), 13% (other group)	unknown	21% women 10% men, at time of the study	yes, mandatory implications counselling

Murray et al. (2003) UK	0%	29%	mean age 4,8 y	not clear	Uncertain
Söderström et al. (2010) Finland	27,7% 0-3 y; 26% 3-14 y	83,3% 1-3 y 44,4% 13-14 y	1-14 y	42,5% women 22% men	uncertain
Laruelle et al. (2011) Belgium	0%	28,6% in known donation; 45,8% in known-anonymous donation; 33,3% in anonymous donation	unknown	few couples asked for counselling spontaneously	yes, 100%

ples received mandatory counselling focussed on the choice of type of donation before oocyte donation and on secrecy or disclosure (Laruelle et al., 2011).

Three other studies reported that counselling focused on specific cases and/or moments, but did not refer to the mandatory or voluntary character of the counselling. One study reported that couples were counselled by a psychosocial worker about specific aspects of donation parenthood before and during treatment (Isaksson et al., 2011). One study reported that couples had a counselling session before oocyte donation treatment (Hahn and Caft-Rosenberg, 2002). One study reported that couples received psychological counselling to guide the decision-making process regarding donation with an anonymous or a known donor and to pay attention to possible psychological consequences of the decision (Baetens et al., 2000).

Need for counselling

In twelve studies it was mentioned that couples were counselled. How many couples actually sought counselling was only known for four studies. For these studies respectively 33%, 35%, 35% and 21% of the couples told the researcher they had wanted counselling (Daniels et al., 2009; Hershberger et al., 2007; MacDougall, 2007; Salter-Ling et al., 2001). In one of these four studies couples expressed a concern about disclosure and wished supportive or therapeutic counselling on this topic both prior to, and during treatment (MacDougall et al., 2007). In thirteen studies, couples had not recognized a need for counselling during treatment, but wished for it in retrospect (Daniels et al., 1995; Daniels et al., 2009; Hahn and Caft-Rosenberg, 2002; Hammarberg et al., 2008; Hershberger et al., 2007; Isaksson et al., 2011; Lalos et al., 2007; MacDougall et al., 2007; Murray and Golombok, 2003; Rumball and Adair, 1999; Salter-Ling et al., 2001; Shehab et al., 2008; Söderström et al., 2010). In one study wherein couples were counselled mandatory before oocyte donation, very few couples had asked for coun-

selling spontaneously, but they brought up disclosure and relational issues when they came for treatment for a second child (Laruelle et al., 2011). The reasons given for seeking counselling were mentioned in thirteen studies and consisted of need for assistance and advice from professionals in the disclosure decision, and information and guidelines on when and how to disclose (Table III).

The content of counselling of parents (to be)

The content of the counselling is summarized in Table III. Only two of the studies reported about the focus in the counselling session before treatment (Baetens et al., 2000; Laruelle et al., 2011). In these studies couples are counselled by psychologists and the aim of counselling was to guide the decision-making process regarding the kind of donation to be used, known or anonymous donation (Baetens et al., 2000) and to compare motivations and attitudes in the decision making process of three types of donation, known donation, known- anonymous donation or anonymous donation (Laruelle et al., 2011). None of the other studies mentioned how couples actually were counselled. Seventeen of the twenty studies mentioned issues that came up in counselling. The disclosure and secrecy issue was mentioned in 10 of the 20 studies (Baetens et al., 2000; Grace et al., 2008; Hahn and Caft-Rosenberg, 2002; Hammarberg et al., 2008; Laruelle et al., 2011; Leiblum et al., 1997; Lindblad et al., 2000; Nachtigal, 1998; Rumball and Adair, 1999; Salter-Ling et al., 2001). In seven studies parents expressed uncertainty about when and how to disclose, the effect on the child and fear that the child would not understand, and how to handle the lack of a genetic tie. They also expressed the wish for more professional support and guidance on this issue (Grace et al., 2008; Hershberger et al., 2007; Leiblum et al., 1997; Mac Dougall, 2007; Murray and Golombok, 2003; Rumbal and Adair, 1999; Salter-Ling et al., 2001). In two of these studies some non disclosing couples expressed that they did not do so, because they felt disclosure is a private

Table III. — Content of counselling.

Author (year) country	Parents disclosed to donor offspring	Parents did not disclose to donor offspring	Issues in counselling	Content of counselling and role of counsellor
Daniels et al. (1995) New Zealand	unknown	unknown	unknown	counsellor is seen as a gate keeper and facilitator
Rumball et al. (1999) New Zealand	30%, (34% < 3y, 30% < 2y, 20% < birth)	55%	disclosure/ secrecy	counsellor stimulated disclosure and early telling, but did not intend when and how.
Grace et al. (2008) New Zealand	34%	27%	donor issues as: resemblance, importance of screening; effect of telling on donor offspring	unknown
Daniels et al. (2009) New Zealand	35%	18%	unknown	until 1985 counselling by med. doctor; after by trained professional counsellors. 7 parents asked assistance from interviewer how to tell their adult child about DI
Durna et al. (1997) Australia	5%	66%	unknown	unknown
Hammarberg et al. (2008) Australia	84%	unknown	- disclosure - possible future interaction donor/ child - lack genetic tie - legal matters	counsellor stimulated disclosure
Leiblum et al. (1997) USA	25%	59%	- disclosure/secrecy some: secrecy is a private issue - tension between intellect and Feeling	1/3 sought counselling, for information, guidance and support. Counselling can be meaningful and is needed for when and how to disclose.
Nachtigall (1998) USA	30%	unknown	what is the best for the child and family	counsellor influenced disclosure decision
Hahn et al. (2002) USA	39%	29% undecided	unknown	discussion with counsellor about what is well, need for real stories
Hershberger (2007) USA	0%, result during OD treatment	1 (of 8) wanted secrecy, 3 undecided	unknown	unknown
MacDougall et al. (2007) USA	32% DI mean age, 7.2 23% OD, mean age 3.6	unknown	unknown	parents wished more professional guidance and support.
Sehab et al. (2008) USA	32% DI, mean age 7.2; 23% OD, mean age 3.6	16% DI 10% OD	unknown	role counsellor more aware in retrospective. In case of OD: had wanted information, options, guidelines and peer support.
Lindblad et al. (2000) Sweden	11%	unknown	disclosure/ secrecy (partly: it is our business to tell or not. It is our child, we decide)	counselling to facilitate parents in how to decide in the disclosure /secrecy issue; need for information and guidance

Lalos et al. (2007) Sweden	61%, 3,5- 5 y	unknown	unknown	counsellor impacted thinking and encouraged disclosure. Need for guidance and support
Isaksson et al. (2011) Sweden	0%, result before GD treatment	unknown, result before GD treatment	unknown	the guidance and support did not meet up the need. The counsellor need to have knowledge of psychosocial aspects about gamete donation
Baetens et al. (2000) Belgium	33%	17% more or less secrecy	- disclosure/ secrecy - information how to tell the child (with both parents, at early point in life) - consequences of GD, future contact donor offspring/donor	counselling couples about negative consequences of GD; How to tell donor offspring (with both parents, at early point in life)
Salter-Ling et al. (2001) UK	unknown	unknown	- disclosure/ secrecy - information about the donor - how to tell donor offspring	professional guidance needed in discussing GD with family and donor offspring. Expression of feelings about donation.
Murray et al. (2003) UK	0%	47%, 24% undecided	unknown	counsellor stimulated disclosure Guidelines needed for when and how to disclose to donor offspring
Söderström et al. (2010) Finland	61%, 27,7% 0-3 y; 26% 3-14 y	unknown	unknown	counsellor should support (56% satisfied), more need for individual counselling (24% mothers, 11% fathers). Help to solve disagreements on disclosure issues and support of counsellor after delivery. Availability routinely after delivery or at time of disclosure (8%)
Laruelle et al. (2011) Belgium	0%, result before GD treatment	unknown, result before GD treatment	- donor type (known, known-anonymous, anonymous) - disclosure/ secrecy - relationship	few couples asked spontaneously for counselling. In case of 2 nd child, couples brought up disclosure and relational issue themselves

decision and should be taken independently, while other couples thought that in future they themselves would feel what would be the right time to disclose to their child. In four studies specific donor issues came up: the resemblance of the father and the importance of screening donors; possible future interaction between donor and donor offspring; reasons for being a donor and the choice for a specific donor and information about the donor (Baetens et al., 2000; Grace et al., 2008; Hammarberg et al., 2008; Salter-Ling et al., 2001). Issues that were raised in

the study wherein couples received ‘implication counselling’ were: information about the medical procedure (95%), information about the donor (80%), and expressing feelings about treatment and DI (70%) discussing issues relating to telling their families (35%), discussing of how to tell their child about DI (35%), (Salter-Ling et al.,2001). In one study, parents brought up disclosure and relational issues when they came for treatment for a second child (Laruelle et al., 2011). In one study parents wanted the counsellor’s help to solve disagreements

on disclosure between them, and/or support after delivery and at the time of disclosure (Söderström et al., 2010). In one of the studies the parents asked the interviewer assistance in how to disclose DI to their adult children (Daniels et al., 2009).

The role of the counsellor with regard to disclosure

In 16 studies some details on the role of the counsellor or counselling were mentioned. The counsellor was seen as gatekeeper and facilitator in one study (Daniels et al., 1995). In five studies the counsellor stimulated disclosure (Hammarberg et al., 2008; Lalos et al., 2007; Murray and Golombok, 2003; Nachtigall et al., 1998; Rumball and Adair, 1999), and in one of these, early telling was stimulated by the counsellor as well (Rumball and Adair, 1999). One of these five studies reported that for clinics it is mandatory to report the identity of the donor to a central register and the counsellors should advocate that parents disclose the donor's origin to the child. 41% of the parents mentioned that the counselling had some effect on disclosure and 26% reported no impact at all. In this study couples were counselled before and after treatment. The donors that were counselled in this study were more likely to believe donor offspring should be informed after the second counselling (Hammarberg et al. 2008). In the second of these five studies offering counselling had been an integral part of the treatment procedure and 94% of the couples took advantage of it. Disclosure at young age was the policy of this fertility clinic (Rumball and Adair, 1999). In the third of these five studies it is mentioned that more than 50% of the parents received -sometimes contradictory- messages about secrecy/ disclosure from the staff. About 65% got the advice: 'do what you want' and in 25% couples which were separately counselled, received an opposite advice (Lalos et al., 2007). In the fourth of these five studies counselling was available, but not mandatory (Nachtigall et al., 1998) and in the fifth is not mentioned if couples received counselling (Murray and Golombok, (2003). In the last two studies nothing is reported about the clinic or health care staff's attitude on the disclosure/ secrecy issue. In nine studies the parents had mentioned that counselling is needed for information, guidance and support regarding disclosure (Hahn and Caft-Rosenberg, 2002; Lalos et al., 2007; Leiblum et al., 1997; Lindblad et al., 2000; MacDougall, 2007; Murray and Golombok, 2003; Salter-Ling et al., 2001; Shehab et al., 2008; Söderström et al., 2010). In two studies, parents had expressed a need for real stories of parents in the same situation, and for peer support (Hahn and Caft-Rosenberg, 2002; Shehab et al., 2008).

Discussion

The present review aimed to provide an overview of all available facts and data on counselling in couples undergoing gamete donation. We found no clear pattern in counselling practices, neither in the views of the counsellors, or of the fertility clinics on the disclosure/ secrecy issue. In twelve of the 20 studies we found that counselling was offered, but not how couples were counselled. In one of these studies the counselling session before treatment was used for the study (Laruelle et al., 2011). The moment when counselling was offered was not clear in 6 of these twelve studies. Only in two studies it was explicitly mentioned that counselling was mandatory before treatment (Laruelle et al., 2011; Salter-Ling et al., 2001). In one study most couples undergoing oocyte donation had been counselled as standard part of the protocol and this was not the case in couples undergoing donor insemination (Shehab et al., 2008). In one other study on only donor insemination counselling was offered as an integral part of the treatment (Rumball and Adair, 1999). The difference in counselling donor insemination couples in the last two studies maybe has to do with the different national attitudes. New Zealand strongly adopted an openness and information sharing approach for the last 20 years, which is legal since 2004, and the USA was divided in liberal en more conservative parts, so the politically liberal environment and the acceptance of gamete donation could contribute to concerns about stigma (Daniels et al., 2009; Shehab et al., 2008). In three of the six oocyte donation studies 100% of the couples received counselling and for the other three studies it is uncertain. The studies were done in five different countries, so it seems that whether couples received counselling depended on the individual clinics. We hardly found any information about whether the counsellor was a medical doctor or a nurse, or a trained professional counsellor with knowledge of psycho-social aspects related to gamete donation, which seems to be important as in about half of the studies couples wished for more professional support and guidance. Moreover, none of the studies reported a psychological or family system theory that was used as a basis for counselling in gamete donation and, especially on the secrecy-disclosure and relational issue. In the studies that mentioned parents were stimulated to disclose, we did not find any theoretical ground for this. Three of these 5 studies reported that this was the policy of the clinic (Hammarberg et al., 2008; Lalos et al., 2007; Rumball and Adair, 1999). One of these three studies reports about the sometimes contradictory attitude of the health care staff of the same clinic (Lalos et al., 2007) and in one study is reported that

the counselling, that was given before and after treatment, had some effect on the parents and more effect on the donors in favour of disclosure (Hammarberg et al., 2008). The subject matters of the counselling were outlined and the counsellors should advocate disclosure, so it is interesting to know why after counselling donors were more convinced about the importance of disclosure to donor offspring than the recipients. No distinction was made between oocyte donation and donor insemination.

Our findings can be summarized as a lack of evidence based protocols and practices on counselling to support disclosure. This is worrisome, because there are indications that disclosure is more beneficial for both the parent and the child than non-disclosure, and that parents often want or intend to disclose, but are uncertain about when and how to disclose and are afraid of the consequences (Akker vd, 2006; Jadva et al., 2009; Rumball and Adair, 1999; Scheib et al., 2005). Besides these indications it would be of interest to know if there are specific ethnic, religious, socio-cultural or family situations in which disclosure could be especially beneficial of difficult for the parents and children. Only one study reports that parent's discussions reflected a variety of influences and contexts as the opinions of professionals, religious background, socio-political environment etc. (Shehab et al., 2008).

Parents have especially concerns about when and how to tell donor offspring, possible future contact of donor offspring with the donor and information on the donor. In several studies of this review parents mentioned that the counsellor encouraged disclosure, but that they did not receive the guidance and support they needed in the disclosure process (Baetens et al., 2000; Hammarberg et al., 2008; Lalos et al., 2007; Murray and Golombok, 2003; Nachtigall et al., 1998). In one study parents stated disclosure or secrecy to donor offspring is a private matter and not a case for professionals (Lalos et al., 2007).

In some studies parents mentioned the specific moments they needed counselling, i.e. at the time of disclosure to donor offspring, in case of treatment for a second child and after birth (Baetens et al., 2000; Daniels, 2009; Laruelle et al., 2011; Söderström et al., 2010).

In view of the sensitivity and importance of the subject and the needs of parents, we suggest that counselling should be available for and offered by professional counsellors with specific knowledge about gamete donation, especially on secrecy, disclosure and relational issues, to all prospective parents at specific moments as before treatment and at the time of disclosure.

A drawback of our review is that the studies included in this review were conducted over a long

period of time, i.e. between 1995 and 2011. During this time, attitudes, legislation and professional guidelines regarding disclosure have changed in many countries. In New Zealand and Australia, attitudes and legislation regarding anonymity and disclosure have changed towards more openness and transparency over the last decades, while in the European countries wherein the studies were conducted legislation regarding anonymity and disclosure is divergent. For instance, whereas HFEA guidelines in the UK recommend that counsellors should encourage disclosure, there are other countries where donor anonymity and secrecy are still obligatory, e.g. in Spain and France. Countries like Belgium and Denmark have a system of donor anonymity, but non-anonymous donation via official routes (i.e. with identifiable donors) is also possible (Janssens, 2011).

Although the data presented in this review describes counselling practices over a period of 16 years, 10 studies were done in the last five years (Daniels et al., 2009; Grace et al., 2008; Hammarberg et al., 2008; Hershberger, 2007; Isaksson et al., 2011; Lalos et al., 2007; Laruelle et al., 2011; MacDougall et al., 2007; Shehab et al., 2008; Söderström et al., 2010).

In nine of these 10 studies 18% to 90% of the couples had the intention to disclose gamete donation. In 6 of the 10 older studies 13% to 100% of the couples intended to disclose. The need for professional guidance and support has been reported in six of the 10 recent studies, especially when and how to disclose (Daniels et al., 2009; Isaksson et al., 2011; Lalos et al., 2007; Laruelle et al., 2011; MacDougall et al., 2007; Shehab et al., 2008; Söderström et al., 2010). In the older studies these issues are also reported, but the need for guidance and support is mentioned in only four out of the ten studies before 2007 (Leiblum et al., 1997; Lindblad et al., 2000; Murray and Golombok, 2003; Salter-Ling et al., 2001). In two of these studies from the nineties the counsellor specifically stimulated disclosure to donor offspring (Nachtigall et al., 1998; Rumball and Adair, 1999).

In all studies, only information about counselling on heterosexual couples was available, which is remarkable because many lesbian couples and single women are also treated with artificial insemination with donor sperm for social indications.

Recently several studies about disclosure in lesbian and single-mother families showed that donor offspring learnt earlier of their donor origins than offspring of heterosexual couples (Beeson et al., 2011; Jadva et al., 2009). In a study on single mother families, almost all single mothers wanted their child to have identifying information. About two-thirds of

them had not disclosed the donor conception to their child, but intended to do so in the future. It is suggested that these mothers experienced how difficult it is to find the appropriate way of sharing information about gamete donation with their child and professional counselling is needed (Landau and Weissenberg, 2010).

It is likely that all parents - whether they are in a heterosexual or lesbian relationship or whether they are single mothers- experience difficulties sharing information with their children about their genetic origin and need professional support in this.

In summary, our review shows that empirical knowledge on counselling of couples who ask for gamete donation, as well as parents with children after gamete donation is limited. To be able to provide good care to couples involved in gamete donation related treatments, especially in relation to the disclosure process to donor offspring, more research is needed. This research should aim to find out more precisely what parents' needs are, when they require counselling to meet those needs and what psychological or family system theories are or can be used as a basis for counselling in gamete donation and on secrecy and disclosure in particular.

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