

Factors contributing to parental decision-making in disclosing donor conception: a systematic review

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BACKGROUND: In recent years, changes in attitudes towards (non-)disclosure of donor conception to offspring and/or others have been observed. Studies have started to identify possible factors that contribute to these changes that are relevant for clinics, counsellors and policy-makers in their approach to the disclosure process. The aim of this systematic review was to integrate the existing knowledge on factors that influence the disclosure decision-making process of donor conception to offspring and/or others in heterosexual couples, and to discuss future trends and concerns.

METHODS: A bibliographic search of English, French, German and Dutch language publications of five computerized databases was undertaken from January 1980 to March 2012. A Cochrane Database systematic review approach was applied.

RESULTS: A total of 43 studies met the inclusion criteria, and these represented 36 study populations. The review shows that the parents' disclosure decision-making process is influenced by a myriad of intrapersonal, interpersonal, social and family life cycle features. These influences were not necessarily independent but rather were interwoven and overlapping. Theoretical frameworks have not yet been used to explain how the different factors influenced disclosure. Methodological limitations of the original publications (lack of information, several factors included in one study, descriptive character of studies) and this review (multiple factors that may interact) which hindered integration of the findings are outlined.

CONCLUSIONS: Intrapersonal, interpersonal, social and family life cycle factors influence the parents' disclosure decision-making process. The review has demonstrated the need for the development of a theoretical model to enable integration of the identified influencing factors. Further research is needed on the role of stigma, confrontation efficacy, extended family, donor siblings' characteristics, cross-border treatment, culture, gender and socio-educational factors.

Key words: systematic review / disclosure / donor insemination / oocyte donation / embryo donation

Introduction

The decision-making process of disclosing the donor conception to the offspring and/or others, or not, is one of the most challenging dilemmas couples face when starting donor treatment (Daniels *et al.*, 2011). This is also reflected in the lack of consensus regarding medical practices, laws and regulations on gamete donation all over the world (Boivin *et al.*, 2001; American Society for Reproductive Medicine (ASRM), 2004; Blyth and Landau, 2004; Jones *et al.*, 2011). Information sharing—often dichotomized and represented as disclosure and secrecy—has been, and to a certain extent remains, one of the most controversial and debated issues between professionals working in the field of third party reproduction. In the past, recipient parents typically opted for secrecy but recent studies reveal that a growing number of parents intend to tell their offspring about the nature of their conception (Golombok *et al.*, 2004; Söderström-Anttila *et al.*, 2010; Isaksson *et al.*, 2012). Early research evolved from surveys with a dichotomous approach of the disclosure issue, to introducing terms—such as 'information sharing and exchange' (Daniels, 1997), 'selective disclosure' (Hershberger *et al.*, 2007) or 'partial disclosure' (Readings *et al.*, 2011). In addition there has been a move to shift from looking at disclosure as a defined 'once in time' act, to the idea of looking at disclosure as an ongoing process (Daniels *et al.*, 1995; Nachtigall *et al.*, 1998; Lycett *et al.*, 2005; Mac Dougal *et al.*, 2007). Subsequently research started to focus more on factors possibly influencing this disclosure decision-making process, with the aim of better understanding the changes in attitudes that were observed. These factors that are influencing the parents' disclosure decision are ultimately important for clinics, counsellors and policy-makers in their approach to assist parents and couples applying for a donor gamete treatment with this issue.

The aims of this systematic review were: first, to integrate the existing knowledge on factors that influence heterosexual couples' disclosure decision-making process about the donor conception to offspring and/or others, and second to point to areas of research that need further investigation.

Methods

Search strategy

A bibliographic search of English, French, German and Dutch peer-reviewed publications in five electronic databases (MEDLINE, CINAHL, EMBASE, PSYCINFO and WEB of KNOWLEDGE) was undertaken for the period January 1980 to March 2012 using the search terms 'artificial insemination heterologous', 'donor insemination', 'third party reproduction', 'oocyte donation', 'embryo donation', 'gamete donation', 'disclosure', 'secrecy' and 'information sharing'. Search terms were used in all possible combinations. A manual search of the references of the included articles was done to identify additional studies.

Study selection

Inclusion criteria: (i) Original empirical research (with a quantitative, qualitative or mixed methodology), (ii) Study participants were heterosexual couples who had made the decision to start a donor treatment or had conceived through sperm, egg or embryo donation. Research that contained mixed study groups (heterosexuals, lesbians, single mothers, adoptive, IVF or parents who conceived naturally) needed to present clearly separated data for the heterosexual participants. The limitation to heterosexual couples was based on the fact that heterosexual couples—in contrast to single, lesbian or surrogacy families—have a father and mother in the household, which means that the child and others were less likely, if at all, to question the child's conception origins. In addition single women and lesbian couples do not face male infertility and the possible reluctance to discuss issues associated with it, whereas they will have to answer their children's questions about the absence of a male parent. Although all parents having used donor conception face challenges (e.g. if, when and how to tell how the family was built with the assistance of a donor), heterosexual couples face unique issues, such as how to deal with the concept of the child having a father and mother and a donor. Taking into consideration the already large number of possible influencing factors within the group of heterosexual couples, it was decided to limit the scope of this review to this group only, (iii) Articles, or a substantial part of the article, needed to focus on the disclosure decision-making process by mentioning it in the title and abstract.

Exclusion criteria: (i) Studies presenting rating data on parents' attitudes to (non-)disclosure. (ii) Papers on surrogacy, lesbian or single mothers were excluded, as explained above.

Screening and quality assessment

The first author (A.I.) independently screened titles, abstracts and full-text reports of all retrieved papers. This was cross-checked by the fourth (K.R.D.) and last author (T.D.). Any disagreements on inclusion/exclusion were resolved by discussion. Subsequently articles were assessed on methodological quality using the protocol recommended for quantitative and qualitative studies (Critical Appraisal Skills Programme) by the Cochrane Database of Systematic Review.

Data abstraction

A structured data extraction sheet was developed. The extracted data included authors' details, year of publication, research features (design, aim, method of data collection and analysis) and factors suggested in literature to influence the disclosure decision (see Table I). Eligible studies which met the methodological quality criteria were read repeatedly and thoroughly examined for relevant data. Extracted data were transferred from each paper to the data sheet by the first author (A.I.). The fourth (K.R.D.) and last author (T.D.) commented on the data collection and analysis process. The fourth author (K.R.D.) reviewed the results for accuracy.

Table 1 Characteristics of studies included in the literature review

Author/Year of publication/ Location of research	RR/Sample size /Type of donor conception	Age offspring (M = Mean)	Research design	Data collection	Recruitment	Law or regulatory agencies/Specific clinic regulation/ counselling practices	Donor	Research aims	Siblings
Adair and Purdie (1996)/NZ	RR DSR parents: 38%; RR DSRdonor: 41% 30 Recipients 9 Donors 7 Donor partners	In treatment, pregnant or having a child	Descriptive	Questionnaires ^a with open and closed questions and clarifying— Men and women separately	4 Clinics + 1 Obstetric practice	Most sperm banks accept only donors who are willing to be identified. No legislation or register yet/ counselling is encouraging openness	Known donor (family, friends)	To examine intentions of personal DSR donors and the recipients on donor identification and donor contact	No information
Baetens et al. (2000)/ BE 45% BE; 30% FR., DE, NL; 7.7% not European	144 OR couples.	Pretreatment counselling	Descriptive Comparative	Observation of semi-structured counselling Couple session and—if known donor—joint counselling with donor	1 Clinic	No ART-regulation, clinics have own rules for acceptance of ART/Clinic offers 'known-anonymous' or 'known' donation/most clinic in BE will respect full anonymity/counselling prior treatment to all OR to guide decision process	Anonymous and known	To explore donor choice, disclosure decision	11.5% biological children from previous or current relationship
Becker et al. (2005)/ USA (Calif.)	Self-selected 148 couples (79 DSR 62 OR, 7 DSR+OR)	Infancy—19 years (majority 1–10 years)	Qualitative	Qualitative semi-structured interview—joint and separate couple	12 Medical practices + 1 Sperm bank + Online adds + Snowball effect	Clinics determine their regulations widely. No information on counselling	Donor selection was determined by the different selection procedures utilized by their medical provider	To explore the meaning of resemblance and resemblance talk for parents	No information
Blyth et al. (2010)/UK	Self-selected 15 DC families (13 DSR, 2 OR) 15 mothers + 12 fathers constituting 12 couples	OR child: 3–6 years DSR child: 5–18 years	Qualitative	In-depth interviews—Men and women separately	2 UK support groups	Support groups promoting disclosure	Not specified	To describe dynamics of parental disclosure	No information
Brewaeyts et al. (1997)/NL	RR DSR: 53% RR IVF: 67% RR NC: 60% 38 DSR families 30 IVF families 30 NC families	4–8 years	Comparative	Couple interview—Men and women separately	1 Clinic	No info on counselling practice	Anonymous	To examine parents' opinions about confidentiality and donor anonymity	Eight of DSR (and IVF) families had children from previous marriage
Brewaeyts et al. (2005)/NL	105 DSR couples: 61% heterosexual, 39% lesbian	Pretreatment counselling	Comparative	Observation of semi-structured couple counselling sessions	1 Clinic	Data collection prior law '04 abolishing anonymity/ counselling integrated in treatment	Anonymous: 37% hetero, 2% lesbians Identifiable: 63% hetero, 98% lesbians	To examine parents' own donor preferences, and examine association between choice of donor and disclosure	No information
Cook et al. (1995)/ UK	RR DSR: 62% RR adoption: 76% RR IVF: 95% 45 DSR families 55 adoptive families 41 IVF families	4–8 years adoption: 6 years M DSR: 5.5 years	Descriptive Comparative	Standardized semi-structured interview, mothers only + Questionnaires ^a	Multiple clinics and adoption agencies	Donor anonymity protected by law/No or little counselling vs. extensive counselling for adoptive parents	Anonymous	To examine the extent and the reasons for DSR parents secrecy	No information
Daniels et al. (1995)/NZ	RR: 89% 58 DSR couples, report on a subset of 48 couples (10 not possible to jointly interview)	Having conceived Age child/ children not specified	Qualitative Retrospective	Semi-structured jointly interview Questionnaire ^a —Men and women separately	1 Clinic	Couples had conceived between 1983 and 1987	Anonymous	To explore the nature of couples' decision-making to and agreement on (non-) disclosure DC to offspring	No information

Daniels <i>et al.</i> (2009)/NZ	RR: 77% 44 DSR families	14–21 years	Longitudinal Pre-post-design	Questionnaires ^a —Men and women separately	1 Clinic	HART act '04 abolishing donor anonymity, encouraging disclosure, volunteer register. 20 years before already culture of openness, though not in law. Counselling in clinic at T1 was non-disclosure	Anonymous	To explore parental attitudes and decision-making over 14 years when professional and socio-political changes occurred	Some had natural conceived children
Daniels <i>et al.</i> (2011)/NZ	12 DSR parents (7 couples) (subset of database of Daniels <i>et al.</i> , 2009)	16–21 years	Qualitative	Qualitative in-depth semi-structured joint couple interviews	1 Clinic	See Daniels <i>et al.</i> (2009)	Anonymous	To explore parents' experiences who decided to inform their adult offspring about the DC	No information
Daniels <i>et al.</i> (2007)/DE	RR: 80% 48 DSR participants (23 couples)	Pre- or in treatment, pregnant, having conceived	Retrospective follow-up study	Questionnaires ^a (open-ended and closed questions)—Men and women separately	Participants of group program (1999–2001)	Group programme supporting disclosure	Anonymous	To evaluate whether preparation group seminars impact on parental confidence and their intention to disclose	Four had an adopted child
Durna <i>et al.</i> (1997)/AUS (NSW)	RR: 70% 276 DSR families (233 couples + 43 single replies)	6 months–17 years	Descriptive Survey Retrospective survey	Questionnaires ^a —Men and women separately but responses were combined to 'family' response	4 Clinics	Donorregisters setting up in Victoria and West Australia, debate on amount of (non-) identifying info that should be stored + if donorregister is necessary next to standard medical record keeping/10 years of pretreatment informative, non-directional counselling	Anonymous	To determine DSR parents' attitudes on disclosing the DC	No information
Golombok <i>et al.</i> (2004)/UK	RR OR: 75% RR DSR: 50% RR NC: 73% 51 OR families 50 DSR families 80 NC families	9–12 months M age = 10.5 months	Longitudinal Descriptive	Questionnaires ^b —Semi-structured interview Men and women separately	9 Clinics	No info on counselling practice	Anonymous: all DSR + 36/51 OR Known: 15/51 OR	To examine the impact of encouragement of openness on disclosure	No information
Gottlieb <i>et al.</i> (2000)/SE	RR: 80% 148 DSR couples	M age intend to tell: 3.5 years M age undecided: 7 years M age non-disclosure: 9 years	Descriptive	Questionnaires ^a + open-ended questions—Joint couple answers	2 Clinics	In 1985 abolishment of donor anonymity, identity release at 'maturity' (18 years)/Clinic staff discussed law with couples and encouraged to disclose/all received counselling	Identifiable	To explore DSR parents disclosure decision and process and satisfaction of their decision who conceived after enactment of the law abolishing donor anonymity	42% had more than 1 DSR child: 18% had different genetically related child(children) (foster, adoption, step)
Greenfeld <i>et al.</i> (1998)/USA	90 OR women	Pretreatment counselling	Descriptive Comparative Cross sectional	Questionnaire ^a —only women	1 Clinic	All had psychological screening	64 anonymous; 26 known (previous known e.g. family or friends; or previously not known e.g. via advertisement)	To determine whether disclosure is correlated to the choice of donor (known or anonymous)	42% had no previous pregnancy and 27% had already a child. No info on genetic relationship
Greenfeld and Klock (2004)/USA (West, Mid-West + East USA)	RR: 31.4%; 90 OR women RR: 31.4%; 90 OR women	2 months - 8 years M age : 2.8 years	Comparative Cross sectional	Questionnaire ^a + open-ended questions—Men and women separately (women in paper)	5 Clinics	East/West and Mid-west clinics, US clinics outline own donor program/All except one paid donors between 1500–10 000 dollars/majority had counselling, no info on content	Anonymous Known	To compare anonymous and known oocyte recipients about disclosure attitudes	23% had child/children who was not donor conceived

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Table I Continued

Author/Year of publication/ Location of research	RR/Sample size /Type of donor conception	Age offspring (M = Mean)	Research design	Data collection	Recruitment	Law or regulatory agencies/Specific clinic regulation/ counselling practices	Donor	Research aims	Siblings
Hahn and Craft-Rosenberg (2002)/USA (Mid-West)	RR: 65% 31 OR couples (31 mothers 27 fathers)	6 months - 5 years M age: 2 years	Qualitative Comparative	Semi-structured interviews Questionnaires ^a —Men and women separately Semi-structured interviews	1 Clinic	No info on counselling practice	Anonymous	To identify factors that influence the disclosure decision and compare between disclosing, non-disclosing and undecided families	52% of families had children of mixed genetic origins (natural conceived, adopted, step)
Hammarberg et al. (2008)/AUS (Vict.)	RR pre: 83% RR post: 47% (81 DSR, OR and ER recipients)	T1 = first counselling session; T2 = after last session	Descriptive Pre-post-design	Questionnaire ^a —joint couple answers	1 Clinic	Vict.:ID, at age 18/Legal requirement to attend at least one counselling session. Infertility Treatment Act (ITA) states that disclosure should be advocated and holds central register	Known: 71% Anonymous: 28% No answer: 1%	To investigate donors' and recipients' views on the value of counselling and impact of counselling on disclosure	No information
Hershberger et al. (2007)/USA	Self-selected sample, 8 OR women	9–23 weeks pregnant	Qualitative	Sequential in-depth interviews— Only women	1 Clinic	No info on clinic policy	Anonymous: <i>n</i> = 7 Known: <i>n</i> = 1	To understand the disclosure experience of pregnant OR women and identify factors that influence their disclosure decision	2 s marriages, one had stepchildren
Isaksson et al. (2011)/SE	RR T1: OR 72% (152 couples) RR T2: OR 49% RR T1: DSR 81% (127 couples) RR T2: DSR 68%	T1: at the start of treatment (no child) T2: 2 months later (38% pregnant)	Prospective Longitudinal cohort study Comparative	Questionnaires ^{a,b} —Men and women separately	All fertility clinics performing donation in Sweden	20 years after law of '85 (since '03 for OR) for IDs/ NBHW 'recommends physicians to make sure future parents disclose'/no info on counselling practice	Identifiable; Known (not in analysis due to low number)	To investigate male and female recipients' attitudes and behaviour regarding disclosure, genetic parenthood and perceptions of received information on donor-parenthood	No information
Klock and Maier (1991)/USA	RR: 50% 41 DSR couples	0–7 years	Descriptive Retrospective	Questionnaire ^a —Men and women separately	1 Clinic	91% had no counselling	Not specified	To report on disclosure attitudes	No information
Klock and Greenfeld (2004)/USA (West, Mid-West + East USA)	RR: 31.4% 92 women + 65 men, containing 62 OR-couples	2 months—8 years M age : 2.8 years	Descriptive Cross sectional	Questionnaire ^a + open-ended questions Men and women separately (Couple's data in paper)	5 Clinics	East/West and Mid-west clinics, US clinics outline own donor programme/ paid donors (1000–25 000 dollars)	Anonymous: 71%; Known from outset: 19%; Known since treatment: 10%	To examine parents' knowledge about the donor and their attitudes toward disclosure	76% reported all their children were OR children
Lalos et al. (2007)/SE	RR 73% 19 DSR couples (19 women, 17 men)	5–15 years M age = 7 years	Longitudinal Descriptive Qualitative	Semi-structured in-depth interview—Men and women separately	2 Clinics	Counselling advise on disclosure was neutral, to non-disclosure or disclosure, to mixed from different staff members	Identifiable (all born after '85),	To examine parents' thoughts on children's right to obtain information on DC and donor, their disclosure behaviour and their experiences of healthcare providers' attitudes	Mentioning other genetically related children in families
Laruelle et al. (2011)/ BE 66.7% Eur (46.7% BE + 41.5% FR); 20% Sub-Saharan; 13.3% N-Africa	135 OR couples 90 OR donors	Pretreatment counselling	Descriptive Comparative	Observation of semi-structured couple counselling session	1 Clinic	Belgian law: adhering anonymity but known donor is allowed + clinic is obligated to offer counselling/ Clinic practice: Counselling is mandatory prior start OR and offered after birth. It supports the decision-making process, no preferred advice	Anonymous; Known-anonymous	To explore recipients' and donors' attitude on disclosure in a known, known-anonymous, and full anonymous system in several cultures	Some had own biologic child(children) from current or previous relation, more couples with known donors had already biologic related child.

Lindblad <i>et al.</i> (2000)/SE	RR: 80% 148 DSR families	1—max. 12 years	Descriptive	Questionnaire ^a with open and closed questions—joint couple answers	2 Clinics	Recruitment after law '85/ both clinics openly positive attitude towards the new law, encouraging disclosure (but respect non-disclosure).	Identifiable	To explore motivations for (non-) disclosure, patterns in reasoning, and experience of disclosure	18% had other genetically related child (adoption, foster, step) + some had a child prior and post law change
Lycett <i>et al.</i> (2005)/UK	RR: 77% 46 DSR families (36 couples)	4–8 years <i>M</i> age: 6.6 years	Comparative	Semi-structured standardized interview—joint couple	1 Clinic	Children born between 1994 and 1998; full anonymity/clinic endorsed openness	Anonymous	To compare feelings and concerns between DSR parents inclining to disclose and those who incline not to disclose	No information
MacCallum (2009)/UK	RR ER:72% RR Adopt: 70% 21 ER families 28 adoptive families	2–5 years	Descriptive Comparative	Standardized semi-structured interview—Men and women separately	3 Clinics 3 Local adoption services	Law ('05) on IDs but all participants had conceived prior 2005/HFEA encouraging disclosure/ Advice on disclosure is less absolute from HFEA than adoption association, also no preparation programme	Anonymous	To assess knowledge of and talking about the donors/birth-parents and disclosure of the DC/adoption to the child. To explore possible gender differences	No information
MacCallum and Golombok (2007)/UK	RR ER:72% 21 ER families	2–5 years <i>M</i> age = 3.5 years	Descriptive	Standardized semi-structured interview—Men and women separately (only data women in paper)	3 Clinics	Prior Law of '85 abolishing anonymity /Counselling can be received but not standard integrated in treatment programme.	Anonymous	To explore the extent and reasons of DC disclosure to the offspring and other family members	No information
MacCallum <i>et al.</i> (2007)/UK	RR ER:72% RR adoptive: 70% RR IVF: 86% 21 ER families 20 adoptive families 30 IVF families	2–5 years <i>M</i> age = 3.5 years	Descriptive	Standardized semi-structured interview—Men and women separately (only data women in paper)	3 Clinics	Prior Law of '85 abolishing anonymity/Counselling can be received but not standard integrated in treatment programme	Anonymous	To explore the extent and reasons of DC disclosure in ER families compared to other forms of family-building	No information
Mac Dougall <i>et al.</i> (2007)/USA (N Calif.)	Self-selected sample of 112 families: 48 DSR and 64 OR	Disclosers: <i>M</i> age OR: 6 years <i>M</i> age DSR: 9.7 years Intend to disclose: <i>M</i> age OR: 2.6 years <i>M</i> age DSR:5.3 years	Qualitative	In-depth semi-structured interviews—Joint and separate couple interview	11 Infertility practices + 1 Sperm bank	Sperm bank of Calif. = open policy encouraging open identity donors/N. Calif. = Known for most social and political liberal region in USA/No info on payment or altruistic donors. In USA for OR typically 1 counselling session is required to discuss treatment	Not specified	How parents envision, plan and enact disclosure to their offspring	No information
Murray and Golombok (2003)/UK	RR: 81% 21 OR mothers	3–8 years <i>M</i> age: 4.8 years	Descriptive	Standardized semi-structured interview—only women	2 Clinics	Clinics selected for their highest number of OR procedures/no info on counselling practice	Anonymous: 14 Known: 3 (family, friend)	To assess extent and reason of disclosure in oocyte recipient mothers	No information
Nachtigall <i>et al.</i> (1997)/USA (Calif.)	RR women: 55% RR men: 46% 176 DSR parents (82 men and 94 women)	2.1 years–8.5 years <i>M</i> age: 5.3 years	Correlational	Questionnaires ^b —Men and women separately	1 Clinic	Counselling was available but not mandatory	Not specified	To examine influence of gender, male infertility and demographics on stigma and disclosure	No information
Nachtigall <i>et al.</i> (1998)/USA (Calif.)	RR: 42% 184 DSR parents (a subset of 156 gave written comments)	no info	Descriptive + Correlational	Questionnaire ^{a,b} Open-ended written comments—Men and women separately	1 Clinic	Counselling was available but not mandatory	Not specified	To identify disclosure concerns & relation between concerns, parents' gender and disclosure stance	No information

Continued

Table I Continued

Author/Year of publication/ Location of research	RR/Sample size /Type of donor conception	Age offspring (M = Mean)	Research design	Data collection	Recruitment	Law or regulatory agencies/Specific clinic regulation/ counselling practices	Donor	Research aims	Siblings
Readings et al. (2011)/UK	RR DSR: 72% RR OR: 63% RR surrogacy: 79% 36 DSR 32 OR 33 surrogacy parents (100 mothers, 73 fathers, constituting 101 families)	7 years	Longitudinal Descriptive Prospective	Standardized semi-structured interviews—Men and women separately	9 Clinics + Surrogacy organization	No information on context	Anonymous	To examine levels of (dis)agreement and the extent to which parents followed through with their original disclosure intentions	Some families had a natural conceived child
Rosholm et al. (2010)/DK	RR start: 80% (1169 women; 1081 men) RR 1 yr: 87.7% RR 5 year: 69.4% 8% DSR or OR	<1–4 years	Longitudinal cohort study Comparative	Questionnaires ^a —Men and women separately	5 Clinics	During study recruitment (2000–2006) only anonymous donors in DK, only heterosexual couples/ Clinical staff advised to disclose	Anonymous	To identify gender, socio-demographic, medical and psychosocial determinants for disclosure	No information
Salter-Ling et al. (2001)/UK	RR clinic sample: 18% 13 women & 12 men (12 DSR couples) DCN: self-selected sample: 11 women and 9 men (9 DSR couples)	Couples in treatment	Descriptive Comparative	Questionnaires ^{a,b} —men and women separately	1 Clinic + DCN	DCN is more supportive to disclosure than clinic policy	Anonymous	To explore concerns and experience of men and women undergoing donor insemination and their intention to disclose	No information
Shehab et al. (2008)/ USA (N Calif.)	Self-selected sample of 141 recipient couples: 62 DSR and 79 OR	M age OR: 3.5 years M age DSR: 7.2 years	Qualitative	In-depth semi-structured interviews—Joint and separate couple interview	11 Infertility practices + 1 Sperm bank	Sperm bank of California, = open policy encouraging open identity donors/N. Calif. = Known for most social and political liberal region in USA/No info on payment or altruistic donors. In USA for OR typically 1 counselling session is required to discuss treatment	Not specified	To describe parents' disclosure decision-making process: contexts, influences and couple dynamics	Some families had child/children with different genetic relation than donor child
Söderström-Anttila et al. (2001)/FI	RR ER-women: 83.3% RR ER-men: 80% 27 ER-couples	12/27 ER-couples had conceived (no info on age), 15/ 27 ER couples had not conceived	Descriptive survey	Questionnaire ^a + open-ended questions + open comments— Men and women separately	1 Clinic	ART law proposal suggest to approve ER/Counselling was included in treatment process and encouraged disclosure	Couples had the opportunity to choose a donor couple that registered identifying information	To explore outcomes and attitudes on disclosure and anonymity among recipients and donors	Four women had offspring with a previous partner
Söderström-Anttila et al. (2010)/FI 83% FI, 17% SE	RR OR mothers: 67.7% (113 mothers) RR OR fathers: 61.4% (100 fathers)	1–14 years	Longitudinal Descriptive	Questionnaire ^a —Men and women separately	1 Clinic	New Finnish law enacted in 2007 (Act 2007) for IDs at age 18/Counselling was included in treatment process and encouraged disclosure	Anonymous: 85% Known: 15%	To examine disclosure prior the Act 2007 and explore parents' attitudes and level of satisfaction up to 15 years after treatment	12% families with different genetically related children

Thorn and Daniels (2007)/DE	Self-selected 23 DSR couples (22 heterosexual, 1 lesbian couple)	Pre- and in treatment, pregnant, had conceived	Qualitative	Semi-structured interview—Joint and separate couple interview	Via doctors expanded to mental health professionals, support group, authors' practice, etc.	Counselling is not integral part of treatment in clinics: 16/23 sought counselling, 6/16 it was mandated by physician, various counselling advice was given. Law uncertainties (e.g. on fatherhood, preservation donor information)	Anonymous	To explore attitudes of couples on disclosure and their argumentations	No information
van Berkel et al. (1999)/NL	RR DSR: 59% 107 DSR couples + 3 women	2–6 years	Descriptive Comparative Replication of study 1980	Questionnaires ^a —Men and women separately	1 Clinic	Counselling policy in '80 was to keep DC secret; in '96 it was neutral ('up to parents')	Anonymous	To compare disclosure attitudes of couples who conceived in 1974–1978 and those in 1990–1994	No information
van Berkel et al. (2007)/NL	RR OR: 64% RR IVF: 62%	OR child: 1.2–5.8 years (M = 3.5 years) IVF child: 1.9–6.5 years (M = 4.2 years)	Descriptive Retrospective	Questionnaires ^a + open-ended questions—Only women	1 Clinic	In NL a known donor is standard in OR treatment; women have to bring their own egg donor/No information on counselling practice	Altruistic known (47% family, 36% friends/, 16% (colleague, via adds etc.)	To explore disclosure in non-anonymous OR-mothers	No information
Yee et al. (2011)/CA	RR OR: 64% (18 women) RR OR donors: 50% (15 women)	In treatment, pregnant or having a child	Qualitative Cross sectional Retrospective	Semi-structured (personal or telephone) interviews—Only women	1 Clinic	Only altruistic donors allowed, no payment/No information on counselling practice	Altruistic known	To explore how disclosure decisions are negotiated by donors and recipients in known oocyte donation	Info on donor's children, but not on recipients' children

Only data from the papers concerning the disclosure topic are included in table (not, e.g. data on parenting, wellbeing, etc.).

DSR, Donor sperm recipients; OR, Oocyte recipients; ER, Embryo Recipients; DC, donor conception; NC, natural conceived; ART, Artificial reproduction technique; HART, Human artificial reproduction technique; DCN, Donor Conception Network; HFEA, Human Fertilisation and Embryology Authority; NBHW, National Board of Health and Welfare.

Known donor = donor recruited by recipients and donor is known to the parents from beginning of off springs' life.

ID = whose identity can be released by the offspring at age 16–18

Anonymous = from the outset, and identity is not available at age 16–18.

Known-anonymous donor = a recipient couple brings a known donor (the symbolic donor) to the clinic, who will donate to an anonymous couple. The recipient couples receives from another anonymous donor.

^aUse of self-constructed questionnaires or no reported information on measurements validity and reliability.

^bUse of questionnaires with information on validity and reliability.

Results

Search strategy and study selection

The screening process is summarized in the study flow chart (Fig. 1). No articles meeting the inclusion and methodological quality criteria were found between 1980 and 1990; 1 prior to 1995, 9 between 1995 and 2000; 10 between 2000 and 2005; 15 between 2005 and 2010 and 8 from 2010 onward. Of the 322 abstracts, 107 were fully read and 43 were included. Of the 64 excluded articles, 54 were not relevant [did not meet inclusion criteria (iii)] and 11 were rejected because they did not meet the criteria of methodological quality assessment (i.e. unclear information on recruited or included population, lacking description of analysis).

Study characteristics

Studies contained information on several factors that potentially influenced the disclosure decision which made comparison of studies very difficult. Nevertheless relevant research data were summarized and are shown in Table I. Studies are ordered alphabetically to simplify searching the table. Research data are organized following a bio-psychosocial model (Daniels, 2005). For reading convenience, the research findings are discussed separately, according to factors which possibly influence the disclosure decision. Nonetheless we realize that the factors are intertwined and have an influence in the day-to-day life of parents.

Country of origin

Nearly half of the articles originated from either the USA (11/43) or the UK (10/43), followed by the Netherlands (4), New Zealand (4) and Sweden (4). The studies took place in 11 different countries, which have a variety of different laws, regulations and guidelines on donor gamete treatments, donor anonymity and donor information.

Research design

Ten studies used a qualitative methodology, 19/43 a quantitative and 14/43 combined qualitative and quantitative methods. The latter group contained studies combining qualitative and quantitative methods in different ways. Some applied deducted pre-codes and analysed them further statistically. Others analysed open comment questions using an inductive qualitative methodology and closed questions statistically, or first carried out an inductive content analysis and subsequently did a statistical analysis. Only Cook et al. (1995) and Nachtigall et al. (1998) clarified the choice for the mixed methodology.

Except for the explorative qualitative studies, the majority of the studies are descriptive (see Table I), and only one study (Nachtigall et al., 1997, 1998) had a correlational design. Eleven studies were comparative and eight studies had a longitudinal/follow-up design. Of these eight studies, two were prospective cohort studies (Rosholm et al., 2010; Isaksson et al., 2011) and four studies compared two time periods with a 4–15-year duration in between (Daniels et al., 2007, 2009; Lalos et al., 2007; Söderström-Anttila et al., 2010). The majority of the studies questioned the participants at one point in time only.

Three studies (Baetens et al., 2000; Brewaeys et al., 2005; Laruelle et al., 2011) collected data from a specific interview setting, that is, pre-treatment counselling. In two studies (Baetens et al., 2000; Brewaeys et al., 2005) no references were made to ethical approval or informed consent. In the third study (Laruelle et al., 2011), the authors refer to a

general convention stating that clinical data can be used anonymously for scientific purposes, signed by patients.

It should be noted that some papers cover data collected from the same population (Nachtigall et al., 1997, 1998; Golombok et al., 2004; Greenfeld and Klock, 2004; Klock and Greenfeld, 2004; MacCallum and Golombok, 2007; MacCallum et al., 2007; Mac Dougall et al., 2007; Shehab et al., 2008; Daniels et al., 2009, 2011; MacCallum, 2009; Readings et al., 2011), including one study population which was used for three studies (MacCallum et al., 2007; MacCallum and Golombok, 2007; MacCallum, 2009), therefore the 43 studies represent 36 study populations.

Participants

Most studies contained a single donor treatment group [whether or not compared with an IVF, natural conception (NC), or adopted group]: 19/43 donor sperm recipients; 11/43 oocyte recipients (OR); 4 embryo recipients (ER) (Zegers-Hochschild et al., 2009). Eight studies included both donor sperm recipients and OR participants: three studies reported the results of donor sperm recipients and OR group separately, three studies did not distinguish between the groups in the result section and two studies only listed them separately when differences were observed.

Sample sizes ranged from 8 couples (Hershberger et al., 2007) to 233 couples (Durna et al., 1997). The wide spread of sample size was influenced by the following variables: (a) the methodology chosen (quantitative versus qualitative), (b) the incidence of treatment (i.e. ER treatment is less common than donor sperm recipients or OR treatments, sample size being around 20 couples, e.g. MacCallum, 2009), (c) accessibility to eligible candidates (Murray and Golombok, 2003: choosing particular treatment centre for recruitment known for its' high incidence of OR treatments; Thorn and Daniels, 2007: expanding the recruitment procedure from medical staff to psychosocial workers and websites), (d) single recruitment location (21/43) versus multiple locations (22/43).

All study populations were self-selected, except in four studies (Greenfeld et al., 1998; Baetens et al., 2000; Laruelle et al., 2011; Brewaeys et al., 2005) where the data were collected during pretreatment counselling. The response rates (RR) of donor sperm recipients were 38–89% with one exception of 18% (Salter-Ling et al., 2001). The RR of OR-recipients was 63–81% with the exception of Greenfeld and Klock (2004: RR: 31%). The RR of ER studies were 72–83.3%. Little is known about the reason why eligible candidates decided not to participate in studies: fear of revealing the donor conception by participation, time pressure and divorce (Cook et al., 1995; van Berkel et al., 1999; Lycett et al., 2005; Hershberger et al., 2007; Daniels et al., 2009; Yee et al., 2011) were reasons expressed by eligible candidates or participants that withdrew. Participants who withdrew from studies were found to be older (Klock and Maier, 1991; Nachtigall et al., 1997; Rosholm et al., 2010), female non-participants were more likely to have tubal occlusion, and male non-participants were starting ICSI treatment (Rosholm et al., 2010). No other demographic differences were observed. Comparing participants and decliners, Hahn and Craft-Rosenberg (2002) found no association between participation and disclosure.

Most (24/43) studies relate to families where the children had not yet reached adolescence (< 14 years), whereas eight studies evaluated the phase prior to treatment or during pregnancy and two studies addressed

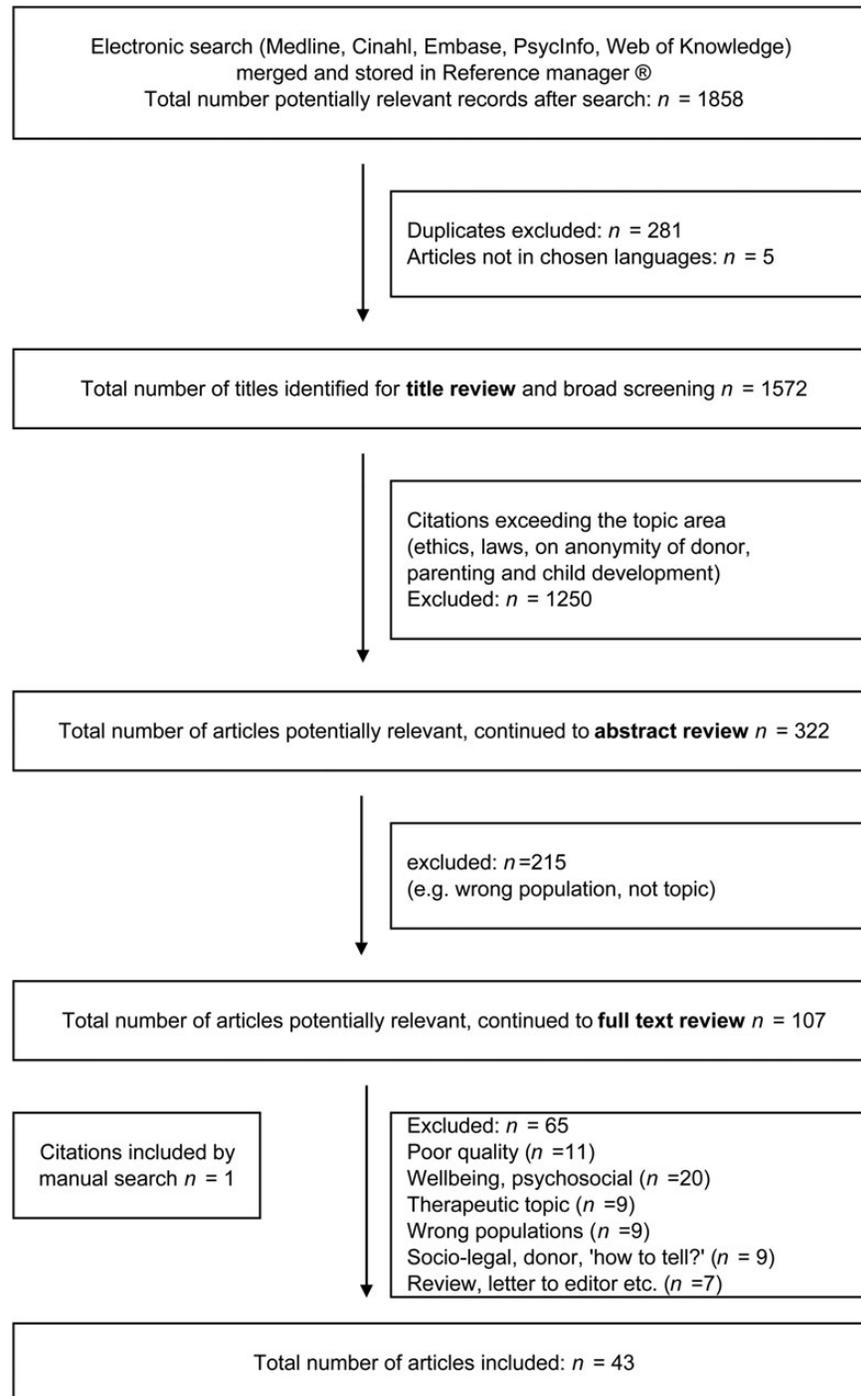


Figure 1 Flowchart depicting selection of articles for review.

the period of adolescence/adulthood (> 14 years). Three studies had a broad age range, from infancy to adulthood (see Table I).

Factors which possibly influenced the disclosure decision were often not described in sufficient detail (see Table I), making it difficult to consider the impact of the factor. This vagueness concerned laws or clinical regulations and available donor information. An anonymous donor (AD) could mean

: 'having no information at all' to 'having various information and a picture' but this was often not specified clearly. Also information on counselling access (mandatory or available) and content (e.g. encouraging disclosure or neutral) was often not detailed enough. As counsellors, clinics and countries apply diverse counselling policies and practices, more detailed information would be needed to explore this possible impact.

Research instruments

Almost half of the studies used questionnaires to collect data and the other half used interviews, whereas three studies used both research instruments (see Table I). All the questionnaires on disclosure were self-constructed without reports on reliability or validity (except for [Nachtigall et al., 1997](#); [Isaksson et al., 2011](#)). Some ([Gottlieb et al., 2000](#); [Lindblad et al., 2000](#); [Söderström-Anttila et al., 2001, 2010](#); [Rosholm et al., 2010](#)) listed the questions used. Interviews ranged from standardized to in-depth formats, and topics of the interview were mentioned in all cases.

The majority (37/43) of studies included both partners (see Table I). Often there was less participation from fathers than from mothers because of work commitments or reluctance to participate. In three studies (see Table I) data were collected from both partners but only mothers' answers was reported on. This could often not be deduced from the article title referring to parents'/families' decision.

Interviews were undertaken jointly with the couple, with both partners separately, or jointly and separately (see Table I). The choice for a joint and/or separate interview was seldom elaborated on. When compared with an individual interview, which could provide both partners with the opportunity to express their personal opinions, a joint interview was felt to potentially elicit more information based on discussion between partners ([Lycett et al., 2005](#)). When compared with an individual interview, a joint interview was felt to potentially elicit more information based on discussion between partners ([Lycett et al., 2005](#)).

Synthesis of the findings

Demographic features

Age of parents. [Baetens et al. \(2000\)](#) observed that the intention to disclose was more prevalent among younger than older recipient couples presenting for an OR programme. Recipient women of ≤ 30 years of age were significantly more inclined to disclose to at least one person, with a similar tendency for their partners. Women who intended to tell the offspring were on average 2.2 years younger than those who did not intend to disclose. A similar pattern was found for the men. Similar results were found in couples who already had conceived; those who intended to disclose or were undecided tend to be younger than those who intend not to disclose ([Hahn and Craft-Rosenberg, 2002](#)). Others ([Greenfeld and Klock, 2004](#)) could not observe any effect of parents' age on the disclosure decision.

Social class and education level. Results on the impact of social class and education level on disclosure are inconclusive. Some investigators ([Nachtigall et al., 1997](#); [Greenfeld and Klock, 2004](#); [Söderström-Anttila et al., 2010](#)) found no association. [Brewaeys et al. \(1997\)](#) observed that a higher level of education led to a higher likelihood to disclose. In contrast, [Rosholm et al. \(2010\)](#) reported that middle and higher social class parents experienced more difficulties in deciding whether to disclose than lower social class parents. The following explanations were presented: 'a more complex process of reflection carried out by higher educated parents', 'higher social class parents being more concerned about keeping up appearances' and therefore being more reluctant to share information that reveals infertility, which might single out their offspring as being different ([Rosholm et al., 2010](#)). [Brewaeys et al. \(2005\)](#), on the other hand, suggested that 'the higher stigmatization in lower socioeconomic context where male infertility and social parenthood remains more of

a taboo and childlessness is less accepted' could explain their observed relation between choice of an AD, lower socioeconomic status and non-disclosure.

Past personal life events. Disclosing parents perceived key events in their personal history—within their family of origin or in social interactions with friends and peers—conducive to disclosure. References were made to open or more inhibited communication patterns in the family of origin ([Hershberger et al., 2007](#); [Shehab et al., 2008](#)) and learning from personal testimonials of donor conceived or adopted family members, friends or acquaintances ([Hershberger et al., 2007](#); [Shehab et al., 2008](#); [Blyth et al., 2010](#)). Only one study ([Shehab et al., 2008](#)) encompassed the views of non-disclosing parents. [Shehab et al. \(2008\)](#) found that, in contrast to disclosing parents, non-disclosing parents made few references to past personal experiences that influenced their disclosure choice.

Gender. [MacDougall et al. \(2007\)](#) pointed to the difficulty with interpreting possible gender differences in disclosure research because past research citing gender differences was primarily conducted with families using sperm donation. In these families it may be difficult to determine whether approaches to disclosure differ between spouses because of gender differences or because of differences in the contribution of gametes. For example, it has been observed ([Daniels et al., 1995](#); [Nachtigall et al., 1998](#)) that women defer to men's feelings about disclosure which could disguise differences.

Looking at the intention or decision to disclose the origin of conception following sperm donation, several investigators ([Brewaeys et al., 1997](#); [Nachtigall et al., 1998](#)) did not detect any gender differences. Moreover, [Brewaeys et al. \(1997\)](#) did not observe differences between fathers and mothers in the reasons for (non-)disclosure. Others observed that women tend towards greater openness than men with regard to disclosure to the offspring ([Daniels et al., 1995](#); [MacDougall et al., 2007](#); [Isaksson et al., 2011](#)) and to others ([Isaksson et al., 2011](#)). In OR families ([Klock and Greenfeld, 2004](#); [Söderström-Anttila et al., 2010](#)) no significant gender differences were found in intention to disclose or actual disclosure to the offspring, but significantly more women than men had told others. However, the majority of OR studies relied on women's reports only. Evidence from ER families showed no gender differences in disclosure stance ([MacCallum, 2009](#)).

Looking more at underlying dynamics possibly explaining gender differences, differences in coping behaviour have been observed: [MacCallum \(2009\)](#) found that ER fathers tended to think less often about the embryo donors than ER mothers and would more strongly adhere to complete donor anonymity than mothers. Although in most cases, both ER mothers and fathers were infertile, ER fathers seemed more reluctant than ER mothers to acknowledge their infertility by considering the role of the donors ([MacCallum, 2009](#)). This observation adds some support to the proposal that men are more likely to cope with infertility by distancing themselves from the problem or by denying its existence ([Peterson et al., 2006](#)). The observation of [MacCallum \(2009\)](#) is also in line with previous findings on gender coping differences (e.g. [Nachtigall et al., 1992](#)). Men were also found to be the least interested in receiving additional information/support about parenthood following donation ([Söderström-Anttila et al., 2010](#); [Isaksson et al., 2011](#)). Also more women than men communicate both factual issues and

emotional aspects of their (general) infertility and the fertility treatment than men (Rosholm *et al.*, 2010).

Infertility diagnosis. No differences in disclosure to the offspring were found based on the cause of infertility (Nachtigall *et al.*, 1997; Greenfeld and Klock, 2004; Daniels *et al.*, 2009; Söderström-Anttila *et al.*, 2010), although those with genetic causes seemed to disclose more but sample sizes were very small (Hahn and Craft-Rosenberg, 2002; Daniels *et al.*, 2009).

In summary: the possible impact of demographic features, such as age, education, and socioeconomic context, on the disclosure decision has only been reported in a few studies, usually as a side issue and results are mostly inconsistent.

Intrapersonal influences

Intrapersonal influences are defined here as processes existing or occurring within the individual self or mind, which may influence the disclosure decision. It has been suggested (Daniels *et al.*, 2007; Thorn and Daniels, 2007) that parents who do not feel confident in their use of donor sperm insemination may be less likely to disclose and that shame and stigma, as a consequence of the infertility, significantly contribute to these lower levels of confidence. Similarly, it has been proposed by Readings *et al.* (2011) that the level of disclosure is—besides parents' perception of their offspring's maturity—affected by the parents' own level of comfort. The impact of stigma on disclosure behaviour was confirmed by Nachtigall *et al.* (1997), Daniels *et al.* (2007) and Laruelle *et al.* (2011). Daniels *et al.* (2007) demonstrated that attending group seminars, where they met other would be parents, and also met an actual family who had two children via donor sperm insemination, increased confidence and impacted positively on the intention to disclose. The isolation and secrecy that tends to be associated with stigma and shame was challenged in a group seminar (Daniels *et al.*, 2007). Feelings of stigmatization were not only associated with the donor gamete treatment (Nachtigall *et al.*, 1997; Daniels *et al.*, 2007) but also with the mode of family building: parents of children conceived by gamete donation address and contest normative definitions of kinship and family that are based on biological connections and resemblances (Becker *et al.*, 2005).

Looking at expressed values and beliefs that guide parents' disclosure decision, all studies (Cook *et al.*, 1995; Brewaeyts *et al.*, 1997; Baetens *et al.*, 2000; Lindblad *et al.*, 2000; Hahn and Craft-Rosenberg, 2002; Murray and Golombok, 2003; Golombok *et al.*, 2004; Greenfeld and Klock, 2004; Lycett *et al.*, 2005; Hershberger *et al.*, 2007; Lalos *et al.*, 2007; MacCallum and Golombok, 2007; Thorn and Daniels, 2007; van Berkel *et al.*, 2007; Shehab *et al.*, 2008; Blyth *et al.*, 2010; Söderström-Anttila *et al.*, 2010; Daniels *et al.*, 2011; Isaksson *et al.*, 2011; Readings *et al.*, 2011; Yee *et al.*, 2011) that addressed this issue mentioned the same moral perspectives, based on rights, principles and best interests. These moral perspectives depended on parents' disclosure stance (disclosure or intend to disclose versus undecided and non-disclosure). Disclosers primarily underlined: 'the child's right to know', 'the principle of honesty' as an essential aspect in building a trusting parent–child relationship, 'best interest of the child' as not knowing would be harmful by undermining his/her sense of self and cultivate shame, 'the difficulties in maintaining the secret', 'the stress attached to it' and consequently 'wanting to avoid accidental disclosure' (by someone else, through medical or technological advances, school

projects or when the child asks itself) and lastly there was 'no reason not to tell'. Undecided couples and non-disclosers emphasized: 'the best interest of the child' by protecting the offspring from possible damaging consequences of disclosure on family relationships, from perceived stigma, 'the right of privacy' and 'no benefit could be identified from disclosure'. They perceived the likelihood that the information could be hidden very deeply and disclosure would only be considered in the event of a medical emergency.

Blyth *et al.* (2010) and Daniels *et al.* (2011) point to the fact that the importance of specific beliefs and values can change over time. 'Increasing' concerns about the potentially negative consequences of non-disclosure have been suggested (Golombok *et al.*, 2004) to result in a greater proportion of parents considering openness with their offspring. Also the value assigned to the right of the child can increase (Golombok *et al.*, 2004; Blyth *et al.*, 2010), as well as the wish for more honest relationships, as the effect of non-disclosure can compromise parents' own integrity (Daniels *et al.*, 2011). Disclosers and non-disclosers were found to have fundamentally different perceptions of the threat that disclosure poses to the wellbeing of the family (Nachtigall *et al.*, 1998). Disclosure (citing honesty as an ethical principle) serves to ameliorate internal threats to the emotional stability of the family that they perceive could result from non-disclosure. Non-disclosure was based on the principle of confidentiality (the right to privacy, personal autonomy and freedom from unwanted intrusion) serving to protect the family against the external threat of social stigma.

Beliefs and values also seem to influence the choice of the disclosure strategy (Mac Dougall *et al.*, 2007). Some couples choose a 'seed-planting strategy' of disclosure based on their convictions that 'their offspring should be informed about their donor conception, in order to avoid a break in trust'. By presenting the donor conception in a 'natural' and 'matter of fact' manner, it would become 'no big deal'. Furthermore, parents felt that 'casual and recurrent sharing of the information within the context of regular family activities reinforced the message that the use of donor gametes was not outside the scope of normal family life'. These couples perceive postponement of disclosure as concealing information and as a signal that the donor conception was something shameful. Other parents opt for the 'right-time strategy' based on their opinion that disclosure at a young age could harm their offspring. They adopt the view that the years leading up to disclosure are an opportunity to establish 'normal', 'familiar' and 'loving' family routines that would allow the parent–child relationship to develop unhindered by the donor information. These couples believe that there is an optimal time in the offspring's development when he/she has developed the cognitive skills to understand the technical and biological procedure of their conception, and the maturity to have a notion of discretion, privacy and public information.

In summary, research has provided evidence for the impact of stigmatization and personal confidence on the disclosure decision process and has documented a relation between moral perspectives and disclosure stances.

Interpersonal influences

Couple dynamics

Existing different opinions within the couple can lead to ambivalence, conflict and dissatisfaction with either disclosure stance, leading to delayed decision-making, or taking others in confidence without the knowledge of the partner (Daniels *et al.*, 1995; Lindblad *et al.*, 2000;

Shehab et al., 2008). However, for the majority of the couples initial agreement existed or was reached after discussion (Nachtigall et al., 1998; Lalos et al., 2007; Shehab et al., 2008). The highest level of agreement was found in the disclosure group, less in the non-disclosure group, and the least in the group that was uncertain about their disclosure decision (Readings et al., 2011). However, other investigators (Lycett et al., 2005) did not find significant differences between disclosing and non-disclosing couples on their level of agreement and how they reached their decision.

The process of coming to an agreement regarding disclosure has been reported to be influenced by the following diverse dynamics (Daniels et al., 1995; Nachtigall et al., 1998; Shehab et al., 2008): the existence of a prior agreement or arrangement (Shehab et al., 2008); the perception that one person was perceived to have more experiential or emotional expertise or greater knowledge and competence (Shehab et al., 2008); greater emotional impact on the future non-biological parent (Daniels et al., 1995; Shehab et al., 2008); impact of the infertility experience (Daniels et al., 1995; Nachtigall et al., 1998); gender differences in coping and socially dictated parenting roles (Daniels et al., 1995). While Daniels et al. (1995) and Nachtigall et al. (1998) point to a pattern of women accommodating their husband's wishes of non-disclosure, Shehab et al. (2008) found that in non-disclosing couples, all women deferred decision-making to their husbands, who preferred non-disclosure. In disclosing couples, men frequently deferred decision-making to their wives, who were more in favour of disclosure (Shehab et al., 2008). A 14-year follow-up study showed that when couples were in initial agreement to disclose or not, this position was maintained over 14 years. In the case of initial disagreement or uncertainty, two-third ended up not telling and one-third did tell (Daniels et al., 2009). There was no research into whether the dynamics of reaching agreement are the same in donor sperm recipients and OR families.

Family influences

Family composition. It has been suggested that OR parents might be slightly more open about the donor conception than donor sperm recipients. Proposed explanations for this difference have included egg donation being a more socially acceptable procedure (Haimes, 1993), the idea that pregnancy and childbirth compensate in some way for the absence of a genetic relationship (Greenfeld et al., 1998), or that the greater proportion of known donors might make future contact between the child and the donor more likely than in donor insemination (Murray and Golombok, 2003). For some OR mothers, experiencing pregnancy and giving birth helped them to cope with being infertile, to establish an identity as a mother and to feel confident enough to be open about the donor conception. For other OR mothers pregnancy helped them to 'forget' about the donor conception or create a view of an own genetic child with no need for telling about the donation. No differences were found in disclosure behaviour between OR parents using an AD and donor sperm recipients (Murray and Golombok, 2003; Golombok et al., 2004; Readings et al., 2011) nor in disclosure concerns, feelings and experiences about disclosure (Golombok et al., 2004; Blyth et al., 2010; Readings et al., 2011) or couple decision-making dynamics (Shehab et al., 2008). The donor conception stories differed in some ways but this could be based on gender distinction as well as 'the varied historical contexts' of the donor sperm and OR treatment (Mac Dougall et al., 2007). Comparing ER families with recent findings of disclosure in donor sperm recipients and OR families (Golombok et al.,

2004), MacCallum et al. (2007) point out that it appeared that ER families, where both parents lack a genetic tie with the offspring, seem to be even more private about the donor conception than donor sperm recipients or OR families.

Eighteen studies mentioned step, adopted, foster or naturally conceived offspring in addition to donor-conceived offspring being part of the family. Only three studies (Baetens et al., 2000; Hahn and Craft-Rosenberg, 2002; Söderström-Anttila et al., 2010) examined the influence of the presence of offspring with other genetic ties to the parent on the disclosure decision and the research findings are inconclusive. Baetens et al. (2000) observed more secrecy, Söderström-Anttila et al. (2010) found no differences and Hahn and Craft-Rosenberg (2002) perceived more disclosure within these specific family formations. The OR families with offspring of different origins in the study of Baetens et al. (2000) and Söderström-Anttila et al. (2010) related to only naturally conceived and donor-conceived offspring. The study of Hahn and Craft-Rosenberg (2002) included more adopted offspring and mothers that had been adopted themselves, which might have influenced participants' disclosure stance. The perceived risk of causing inequality between the siblings and the possibility that they would be treated differently was suggested to influence their decision.

Studies on families with multiple donor offspring present mixed findings. There are no data on how the disclosure decision can be influenced by the existence of multiple donor siblings born in different law systems or when multiple donor siblings were conceived as a result of different donors. One study (Lycett et al., 2005) revealed that the group of non-disclosing families contained significantly more families with two or more donor offspring than the group of disclosing families. The investigators suggested that couples who had an offspring older than the 4–8-year-old offspring that was included in the study, might already have made the decision not to disclose the donor conception to their oldest offspring who was born in a climate where disclosure was not encouraged. However, other investigators (Nachtigall et al., 1997; Shehab et al., 2008; Daniels et al., 2009) reported that the possibility of disclosure was enhanced by having more than one donor offspring. This was explained by a greater comfort with the donor issue (Nachtigall et al., 1997) or siblings being able to share experiences and support each other emotionally (Shehab et al., 2008). Daniels et al. (2009) reported that although couples with naturally conceived and donor-conceived offspring seemed more likely to tell, but due to small sample size this could not be assessed statistically. Overall, the research findings on the possible impact of the number of donor-conceived offspring within a family on the disclosure decision are inconclusive.

Offspring's age. The most common reason given by parents who intended to tell but had not yet done so was that their offspring was too young (Lindblad et al., 2000; Readings et al., 2011). The following factors have been reported to be a main concern in the disclosure decision process and may be a deterrent for parents in carrying through with disclosure (Greenfeld and Klock, 2004; Lycett et al., 2005; Lalos et al., 2007; Mac Dougall et al., 2007; van Berkel et al., 2007; Daniels et al., 2011): 'lack of knowledge about the best age for disclosure', 'the right moment for both the oldest and the youngest offspring' and 'relevance of the offspring's comprehension of the disclosed information'. The parent's view on an appropriate age of disclosure varies between 7 and 11 years, with offspring younger than 7 years being perceived as

too young (Readings *et al.*, 2011). Some patients opt for disclosure at the age of 18 years (Lycett *et al.*, 2005). Disclosure to adolescents was to be avoided as they would be unreceptive to their parents (MacDougall *et al.*, 2007) but has the advantage that adolescents understand the biology of conception (van Berkel *et al.*, 2007). Parents using a 'right-time strategy' believed that there was an optimal time in the offspring's development where the offspring was best able to receive and comprehend the information. The offspring's age was an important factor (MacDougall *et al.*, 2007). Couples using a 'seed-planting' strategy were convinced that early disclosure was of paramount importance and they preferred the offspring to have always known (MacDougall *et al.*, 2007). 'Right-time strategy' parents expressed a greater level of uncertainty about the disclosure plans and more concern about how the offspring would react than did the 'seed-planting parents' (MacDougall *et al.*, 2007). In one study on parents with adult offspring (Daniels *et al.*, 2011), the parents expressed a link between the influence of their offspring's age on their disclosure stance with a desire to be less paternalistic towards their adult offspring.

Alongside age, other important considerations in the disclosure process include the offspring's personality and maturity, and the degree to which the offspring is 'socially and academically settled' (MacDougall *et al.*, 2007; Readings *et al.*, 2011).

Offspring's gender. Lalos *et al.* (2007) remarked that the offspring's gender could influence the disclosure. Girls, by asking more about where babies come from and being more interested in baby-stories than boys, seemed to encourage parents to disclose earlier (Lalos *et al.*, 2007). Although presented as a possible 'gender-effect' it might be the 'interactive factor' (parents being triggered by the offspring) that is causing the effect. These findings seem to be an example of the more interactive process favoured by parents using the seed-planting strategy (MacDougall *et al.*, 2007). The notion of the offspring as an active agent, by triggering parents in their disclosure process, is also mentioned by Yee *et al.* (2011).

Offspring's appearance. Three studies (Lindblad *et al.*, 2000; Becker *et al.*, 2005; Shehab *et al.*, 2008) report on the impact of the offspring's appearance on disclosure. 'Resemblance talk' (comments on the presence or absence of resemblance to the parents) sometimes led parents toward disclosure to clarify and prevent children from feeling confused, in order to prevent stigmatization of their offspring or prevent doubt on the legitimacy of the family structure. However, it was also raised (Becker *et al.*, 2005) that resemblance talk could make discussion more difficult for parents, instead of easier, as they are repeatedly confronted with the primacy of genetic connectedness.

Features of linkage between parents and donors

It has been suggested (Cook *et al.*, 1995) that recipient couples who have more information about the donor may be more inclined to disclose to their offspring. Telling the offspring about the donor conception without being able to provide them with donor information can be perceived as a risk. Parents worried about the lack of identifying donor information on the offspring's identity development (Cook *et al.*, 1995; Brewaeys *et al.*, 1997; Lindblad *et al.*, 2000; Lycett *et al.*, 2005; MacCallum, 2009; Blyth *et al.*, 2010). On the other hand, parents do not always want to receive more donor information (MacCallum, 2009), or want only non-identifying instead of identifying information (Golombok *et al.*, 2004). Parents who intended to inform their child were more in favour of identifying donor information (Brewaeys *et al.*, 1997, 2005) which was reflected in their choice of an AD or identifiable donor (ID). Not

surprisingly, when given a choice in the type of donor, almost all in favour of an ID intended to disclose at the start of treatment, whereas an AD was associated with a higher intention of non-disclosure (Brewaeys *et al.*, 2005). Recipients choosing an ID were more likely to have a higher educational level than those choosing an AD (Brewaeys *et al.*, 2005). Although the study of Brewaeys *et al.* (2005) included 40% lesbian couples, these results only apply to the heterosexual couples as differences between those who choose an AD or an ID were only assessed for the group of heterosexual couples. Therefore the lesbian couples were left out of the analysis of the differences between those couples choosing an AD or ID.

Nevertheless, Swedish and Finnish donor sperm recipients or ER, who generally supported disclosure, were much less affirmative of disclosing the possibility of access to the identity of the donor. Many seemed uncertain about what to expect from a future meeting between offspring and donor (Söderström-Anttila *et al.*, 2001; Lalos *et al.*, 2007; Isaksson *et al.*, 2011). In ER families, the possibility that the child might have genetic siblings made the decision even more complicated (Söderström-Anttila *et al.*, 2001).

When compared with treatment with donor sperm, treatment using donor oocytes has traditionally relied more heavily on known donors. The subsequent assumption of using a friend or relative as an egg donor is that OR parents will be more likely to disclose to their offspring (van Berkel *et al.*, 2007). van Berkel *et al.* (2007) indeed observed higher rates of disclosure and less regret concerning disclosure, when they compared their results with studies on groups using an anonymous oocyte donor or groups with a mixed (anonymous/non-anonymous) composition (Söderström-Anttila *et al.*, 1998; Klock and Greenfeld, 2004; Murray *et al.*, 2006). However, comparison within one study-design between couples choosing an AD and those choosing a known donor has not revealed significant differences in their plans to inform the child, according to most investigators (Baetens *et al.*, 2000; Greenfeld and Klock, 2004; Söderström-Anttila *et al.*, 2010). The study of Greenfeld and Klock (2004) revealed that 88.8% who choose an anonymous oocyte donor versus 70% of those choosing a known oocyte donor had a higher education degree. Greenfeld and Klock (2004) point out that the direction of the relation between education level and choice of donor needs further investigation. Nevertheless, in one study (Greenfeld *et al.*, 1998) a higher likelihood of disclosure to the offspring and others was observed in OR couples choosing a known donor compared with those choosing an AD. Interestingly, in yet another study (Laruelle *et al.*, 2011) disclosure rates were similar among OR couples choosing a known or AD but higher in the known-anonymous group (recipients bring a donor to the centre but receive oocyte from the donor of another recipient couple). Although OR participants in the study of Baetens *et al.* (2000) choose ADs to establish explicit boundaries, the decision to tell the offspring was not significantly related to any characteristic of the donor. In both studies (Baetens *et al.*, 2000; Laruelle *et al.*, 2011), it was hard to interpret the results owing to many factors simultaneously influencing the disclosure decision-making process: 'considerable number of cross-border fertility patients', 'different ethnic and cultural backgrounds', 'use of a known-anonymous oocyte donor to guarantee anonymity or enhance pregnancy-rates', and 'use of a known donor in a country where most fertility centres respect full anonymity'.

Few studies have explored disclosure issues in known donation, where both pre- and post-donation relationships between donors and

recipients may impact the disclosure decisions (Hershberger et al., 2007; Yee et al., 2011). Yee et al. (2011) describe the following key elements that may influence the disclosure decision: (i) at least some members of the donor's and/or recipient's family and/or social network are likely to know about the donation, including the identity of the donor and/or recipient; (ii) the donor and recipient share a familial or social relationship prior to the donation that is likely to continue into the future and will most likely include the donor-conceived offspring and any offspring of the donor; and (iii) where the donation takes place between family members, the donor-conceived offspring will share a family relationship as well as a genetic relationship with the donor and any of her offspring (Yee et al., 2011). While the oocyte donor's preference for disclosure may be a factor in disclosure decisions, the extent of control by the donor is unknown, and little research exists that could enhance understanding in this area (Hershberger et al., 2007). Available data show that mostly agreements were made prior to treatment and the majority of OR (van Berkel et al., 2007; Yee et al., 2011) and oocyte donors (Yee et al., 2011) report agreement regarding disclosure. Agreement was reached by discussion or by leaving the decision up to the recipients. Considerable ambiguity existed regarding the optimum age for disclosure. Whatever age for disclosure to the offspring is agreed between the donor and the recipient, the offspring of the donor are generally more likely to reach that age first, as the donors will mostly have donated after having their own children. In the only study on known sperm donors, the strong sense of debt felt by recipients was reported to lead to the situation where some recipients accepted the request from the donor to remain anonymous (Adair and Purdie, 1996).

Understanding the reason behind the choice of an AD or known donor can shed more light on the disclosure decision. Sometimes a known donor appears to be chosen by donor egg recipients because of 'fears associated with the unknown genetic origin of an anonymous oocyte donor', 'wanting similar physical characteristics', 'wanting a genetic link between donor and recipient' or 'dissatisfaction with the treatment program's choice of donor' (Baetens et al., 2000; Greenfeld and Klock, 2004; Laruelle et al., 2011). The choice for an AD was explained by 'the wish to support and protect the mother-child' relationship, and 'have clear boundaries and roles within the family' (Baetens et al., 2000; Greenfeld and Klock, 2004; Laruelle et al., 2011). Both above mentioned choices—for a known or AD—seem mainly based on the couple's need for reassurance rather than the possibility of future accessibility of the donor to the offspring. Other couples decided on a known donor because they wanted later on to be able to give their offspring information on his/her genetic background and/or wanted the offspring to have access to his/her origin (Baetens et al., 2000; Greenfeld and Klock, 2004; Laruelle et al., 2011). Moreover Stuart-Smith et al. (2012) highlighted the scope for attitudes to donor information to undergo change over the course of treatment and after giving birth. At the start of treatment the choice of an unknown donor was motivated by a wish to feel secure in the role of mother as well as to avoid possible intrusions into family relationships. In the preconception phase of treatment, some participants wanted more information about the donor but others adopted a not knowing stance that protected them from the emotional impact of needing a donor. Curiosity about the donor intensified after birth, and disclosure to the offspring seemed more daunting when very little was known about the donor compared with the situation when donor information would be available (Stuart-

Smith et al., 2012). More research is needed on the direction(s) of the relations between the disclosure stance and donor features.

It should be pointed out that the terminology of 'AD' reflects a wide range of available non-identifying donor information which should be taken into account when interpreting study results. Nonetheless, as Greenfeld et al. (1998) in their study on OR point out, it remains unclear whether the amount of donor information influences the disclosure decision among recipients, or whether the disclosure stance affects their choice of a known or AD.

Extended family and friends context

Many studies (Baetens et al., 2000; Gottlieb et al., 2000; Murray and Golombok, 2003; Golombok et al., 2004; Klock and Greenfeld, 2004; Lycett et al., 2005; Lalos et al., 2007; Rosholm et al., 2010) have reported that parents tell at least one other person about the donor conception, even when they did not disclose or did not intend to disclose the origin of conception to the offspring. Nevertheless few studies (Hahn and Craft-Rosenberg, 2002; Shehab et al., 2008; Söderström-Anttila et al., 2010) address how the interaction between the (future) parents and the extended family or close friends might influence the parents' disclosure decision. Parents have been reported to feel apprehensive about their family's religious convictions or cultural beliefs and how their offspring would be perceived and treated by family members upon disclosure (Shehab et al., 2008). When receiving support from their own parents, siblings, in-laws and extended families, it was easier to disclose the origin of conception to the offspring. But when a lack of family emotional support was anticipated, the disclosure decision was experienced to be more complex and was often associated with anxiety (Shehab et al., 2008). Söderström-Anttila et al. (2010) observed that, when compared with disclosers, non-disclosers were more strongly influenced by the opinions of family members and others. However, other investigators (Hahn and Craft-Rosenberg, 2002) reported that most parents were not being influenced by the family in their decision-making on (non-)disclosure and referred to self-reliance as being more important in decision-making than dependency on social approval. The level of perceived personal social support was similar for disclosing, non-disclosing and undecided parents (Hahn and Craft-Rosenberg, 2002).

Reasons for non-disclosure to the family can include: 'to protect the offspring from being treated differently', 'concern about family disapproval', 'not understanding' and 'the right for privacy'. Reasons for disclosure were: 'wanting to share/to be honest', 'to share confidential information' and 'to discuss psychological issues related to the donor treatment', 'no reason not to tell', 'they already knew', 'looking for support' and 'nothing to be ashamed of' (Klock and Maier, 1991; Baetens et al., 2000; MacCallum and Golombok, 2007; Blyth et al., 2010). Yet parents were selective in the people they decide to inform: the recipients' parents were less likely to be informed than the recipients' siblings, and friends were more likely to be told than family members (Adair and Purdie, 1996). Maternal grandparents and siblings were significantly more likely to be informed than paternal grandparents (Cook et al., 1995; MacCallum and Golombok, 2007). However, donor sperm recipients were more concerned about rejection by non-genetic grandparents than OR parents (Golombok et al., 2004). On the other hand, OR parents feared disapproval from mothers- or sisters-in-law, as some OR women perceived their infertility as diminishing their status

as a 'real woman'. This fear has been reported to be present, especially of other women who have been able to conceive naturally (Murray and Golombok, 2003; van Berkel *et al.*, 2007).

In summary, less attention has been given to research on the influence of couple dynamics, the family composition or the extended family and friends compared with the offspring's age and donor characteristics. The impact of the offspring's age is more evident, whereas findings on the influence of the amount of donor information on the disclosure decision are mixed, and the direction of the relation is still unclear. Owing to methodological issues and differences in the socio-cultural-legal context, it was difficult to compare studies.

External context and social influences

Professional environment

Most couples recognized the potential value of counselling, although they had not recognized a need for counselling during treatment but in retrospect wished they had received it (Shehab *et al.*, 2008). The lack of support and specific disclosure 'scripts' has been raised (Cook *et al.*, 1995) as a determinant for non-disclosure. Parents expect from counselling an opportunity to openly discuss the disclosure topic prior to, during and after treatment without pressure to tell, with specific focus on the following subjects: 'information on telling-scripts', 'best age for telling' and 'consequences of disclosure to their offspring and themselves'; 'written online resources' and 'the possibility to get in contact with other donor families' (Cook *et al.*, 1995; Salter-Ling *et al.*, 2001; Hahn and Craft-Rosenberg, 2002; Greenfeld and Klock, 2004; Lalos *et al.*, 2007; Mac Dougall *et al.*, 2007; Hammarberg *et al.*, 2008; Shehab *et al.*, 2008; Söderström-Anttila *et al.*, 2010).

Research findings on the effect of counselling are inconclusive: some found an indistinct effect (Hahn and Craft-Rosenberg, 2002; Greenfeld and Klock, 2004; Lycett *et al.*, 2005; Hershberger *et al.*, 2007; Thorn and Daniels, 2007) and others (Durna *et al.*, 1997; Lalos *et al.*, 2007; Hammarberg *et al.*, 2008; Daniels *et al.*, 2009; Blyth *et al.*, 2010) observed that for some participants, counselling led to a more positive attitude towards disclosure. Particularly parents using the 'right-time' strategy complained of a lack of information on telling-scripts (Mac Dougall *et al.*, 2007). It is not clear whether this reflects a lack of availability of guidance or a level of ambivalence in initiative or motivation of these parents—as these participants were not accessing or using existing educational materials. 'Seed-planting' strategy parents were more likely to embrace other material, i.e. from adoption, incorporating it in their life story. The availability of educational material that can be personalized to their own situation has been reported to be important (Blyth *et al.*, 2010).

Parents frequently reported that their needs were not met by the support and guidance given by clinics (Lalos *et al.*, 2007; Söderström-Anttila *et al.*, 2010; Isaksson *et al.*, 2011) which focused more upon practical aspects (medical and donor issues) rather than on emotional or interpersonal recipient issues (Salter-Ling *et al.*, 2001). They expressed a wish for more individualized counselling, in contrast to being directed to a specific disclosure or non-disclosure stance without their personal circumstances and views being taken into account (Brewaeyts *et al.*, 1997, 2005; Shehab *et al.*, 2008; Söderström-Anttila *et al.*, 2010).

It is important to note that fertility counselling varies in accessibility (mandatory to everyone or specific groups, available or an integrated part of the programme), content [screening, encouraging (non-) disclosure or guiding the decision process] and between countries/

states, clinics or even professionals (Lalos *et al.*, 2007; Shehab *et al.*, 2008; see Table I). Consequently, participants between study groups, and even within a study group, could have received different guidance, making it difficult to observe possible significant effects of counselling on the disclosure decision-making process.

Parents' experiences of staff attitudes towards (non-)disclosure was only assessed in two studies (Lalos *et al.*, 2007; Shehab *et al.*, 2008). In these studies, health care staff had impacted on the parents' disclosure decision. Furthermore, parents often mentioned receiving unclear and sometimes conflicting messages from staff (Lalos *et al.*, 2007). Mental health professionals were reported as being unanimously encouraging of disclosure, whereas physicians were more variable in the advice they gave (Shehab *et al.*, 2008).

Support groups

The exchange of experiences and support from couples in the same situation, often in the form of professionally led groups (Shehab *et al.*, 2008) or a group preparation programme (Daniels *et al.*, 2007), was mentioned several times as a main influencing factor in the decision-making process (Mac Dougall *et al.*, 2007; Thorn and Daniels, 2007; Blyth *et al.*, 2010). Peer support reduces feelings of isolation and stigma by normalizing the donor experiences and provides for information acquisition derived from the shared personal, lived experiences of other parents in the same specific life situation. Although couples greatly valued peer support, they had difficulty finding other parents in similar situations with whom to discuss the issue of (non-)disclosure (Thorn and Daniels, 2007).

Socio-cultural-legal context

Social stigma. Living in a progressive socio-legal-cultural area (such as northern CA, USA) has been reported to make the disclosure decision easier, as the donor offspring will be more accepted by others (Shehab *et al.*, 2008). The prevalence and acceptance of assisted reproduction techniques (ART), existing models for alternative family structures (e.g. adopted, single parent, gay/lesbian, multiracial, multicultural family structures) and a politically liberal environment contributed to a decreased concern about stigma (Shehab *et al.*, 2008). Similarly, in a 15-year follow-up study, other investigators (Söderström-Anttila *et al.*, 2010) observed a higher likelihood of disclosure in families with young children, possibly explained by a time-related change of culture and increasing acceptance of infertility treatment with donor gametes. Indeed, fear of societal rejection is identified as a main factor in the decision not to disclose (Thorn and Daniels, 2007). Lower scores on perceived stigma have been reported to enhance the likelihood of disclosure (Nachtigall *et al.*, 1997). On the other hand, the feeling of stigma and taboo concerning donor sperm insemination was enhanced by a lack of information and literature, reserved or even rejecting attitude of professionals and unclear legislation (Thorn and Daniels, 2007).

The predominant Western societal discourse that families are based on a biological connection is often expressed through comments about physical appearance or 'resemblance talk' (Becker *et al.*, 2005). This 'resemblance talk'—as cited earlier—can stigmatize the offspring or cast doubt on the legitimacy of the family structure, thereby making disclosure less likely. Gamete recipients from North or Sub-Saharan Africa, whose perspective was included in only one study (Laruelle *et al.*, 2011), are less in favour of disclosure when compared with European gamete recipients, possibly related to a lower acceptance of

infertility and/or third party reproduction in their culture or religion, even for those residing in Europe.

However, sometimes the perceived stigmatization could not be confirmed by actual stigmatization, suggesting the existence of rather perceived fear, at least in some parts of society. The choice of whom to disclose may have influenced the received response (Salter-Ling et al., 2001; Thorn and Daniels, 2007; Isaksson et al., 2011).

Legislation and culture. The impact of legislation on parents' disclosure decision is unclear. It is difficult to separate the possible impact of regulations from cultural changes in attitudes over time. Modifications of legislation and regulations to encourage disclosure do not guarantee actual change in disclosure patterns (Gottlieb et al., 2000; Lalos et al., 2007; MacCallum and Golombok, 2007; Daniels et al., 2009; Isaksson et al., 2011). The observation that Finnish ER parents in the study of Söderström-Anttila et al. (2001) intended more often to disclose when compared with ER parents in the UK (MacCallum et al., 2007) has been explained partly by cultural differences. MacCallum et al. (2007) refer to the fact that Finland had no explicit legislation regarding ART in place when the research was conducted but the fundamental principle guiding the use of such treatments emphasized the rights and interests of the child, whereas the UK equalizes the rights of parents to those of children. In Finland, the majority of OR parents were unsure or expected the new legislation not to have any impact on future parents' disclosure decisions (Söderström-Anttila et al., 2010). Regardless of their disclosure stance, parents have been reported to see the disclosure decision as private and personal, not to be regulated in any way (Shehab et al., 2008). Furthermore, cultural changes (public opinion favouring openness, counselling more liberal, promoting avoidance of secrecy), without legal changes, may have little influence on actual disclosure behaviour (van Berkel et al., 1999). Indeed in a group of donor sperm recipients, the number of couples adhering to absolute anonymity and non-disclosure to the offspring remained the same but more couples intended to tell, and openness towards others and the desire for un-identifying donor information increased (van Berkel et al., 1999). Follow-up research is needed to identify if the intention to tell will result in actual disclosure.

In summary, an impact of health care staff and support groups on disclosure has been demonstrated. Studies on the possible effect of counselling are inconclusive, partly because study results are very difficult to compare. There is evidence of a societal influence on disclosure through perceived stigma. The impact of legislation on parents' disclosure decision is unclear.

Influences of the family life cycle

Several studies (Daniels et al., 1995, 2011; Salter-Ling et al., 2001; Klock and Greenfeld, 2004; MacCallum and Golombok, 2007; Blyth et al., 2010; Söderström-Anttila et al., 2010) refer to the possible influence of the various stages in a life-span (from childless couple through to pregnancy and birth, to infancy, childhood, adolescence and adulthood) on parents' disclosure decision. In one study (Blyth et al., 2010) getting donor information was not a high priority for parents at the outset when their main concern was to achieve a pregnancy. At that moment, donor information was more related to their own health and infertility as couple but at some point they perceived the donor information as the offspring's information. Others (Klock and Maier, 1991; Klock and Greenfeld, 2004; Söderström-Anttila et al., 2010) have reported that parents

regretted disclosing the donor conception to others during pregnancy as—once the child was born—they were concerned about the privacy of the information or saw the situation more from the offspring's point of view.

Indeed, the main preoccupation of gamete recipient couples undergoing treatment is becoming pregnant whereas families with donor gamete offspring were more concerned about sharing the information with the offspring and had fears about the consequences for their relationship (Hershberger et al., 2007). Not surprisingly, the disclosure decision process is influenced by the fact that the disclosure decision regards a 'future' situation, not at all guaranteed at the moment of treatment with donor gametes (Salter-Ling et al., 2001). Parents have criticized clinics and infertility support groups for being too pregnancy oriented, and have expressed a need for guidance not only initially but also continuing long after birth, as disclosure is seen as an ongoing process throughout the offspring's life (Murray and Golombok, 2003; Brewaeys et al., 2005; Mac Dougall et al., 2007). In one study on parents of adult offspring (Daniels et al., 2011), the offspring's age seems to play a part in the parents' desire to be less paternalistic towards their adult offspring, thereby influencing their disclosure stance.

The literature demonstrates that couples' and/or parents' views concerning disclosure shift according to which stage of the family cycle—namely preconception, pregnancy, birth and other specific developmental stages of their offspring's life—they are at. It is therefore suggested that, when inquiring as to couples' or parents' views concerning disclosure, the stage at which these groups are at in the 'family cycle' should be taken into account. The fact that these views may shift according to which stage of the family cycle these groups find themselves must also be acknowledged.

Discussion

Current state of research and future direction

The literature review demonstrates that parental decision-making of disclosing the offspring's mode of conception is influenced by a myriad of intrapersonal, interpersonal, social and family life cycle features. These influences were not necessarily independent or mutually exclusive but were rather interwoven and overlapping.

In addition, the review shows that most of the research designs in this area were generally descriptive in nature. The fact that specific research hypotheses were seldom proposed reflects the early developmental stage of research in this field. As a result, this review points to the lack of an explanatory theoretical framework in which the studies are situated. Without a tentative explanatory theoretical framework, the likelihood of stagnation at a descriptive level is very high. A theoretical framework that proposes a possible model on how these factors impact the disclosure decision and how they might interrelate would lead to integration and advancement of knowledge and would identify future research endeavours more clearly. Furthermore, the application of a theoretical framework could lead to the establishment of more international comparative research studies as it can help to clarify and assess in a more structured way the impact of factors that differ through socio-legal-cultural contexts. In response to this, we introduce the model proposed by Steuber and Solomon (2011). The model originates from research examining how individuals conceal and reveal secrets (Baxter and Montgomery, 1996; Vangelisti and Caughlin, 1997, Afifi

and Guerrero, 2000; Petronio, 2002; Afifi and Steuber, 2009; Greene, 2009) and was expanded with individuals' and spouses' information management within their social networks during the time of infertility (Afifi and Steuber, 2009, 2010; Steuber and Solomon, 2010, 2012) and the notion of privacy management because co-owning infertility information complicates the information sharing.

Main factors of the model are: assessed risk (for myself, the relationship and others), confrontation efficacy (confidence in discussing the topic with others) and closeness in relationships (closeness involves feelings of trust that promotes private disclosure). The model needs further adaptation from a dyadic context to a family context, as the offspring is co-owner of the donor information.

This proposed model, as well as our review, demonstrates the central role of assessed risk/stigmatization (Nachtigall *et al.*, 1997) and confrontation efficacy/confidence level (Daniels *et al.*, 2007) in the disclosure decision process. The other factors mentioned in the review that influence the disclosure decision appear to enhance or diminish the influence of these two main factors. The model helps one to identify factors influencing the disclosure decision that need further investigation.

First, it is not clear if the perceived stigma in parents' risk assessment coincides with actual stigmatization. In the area of ART, public perceptions of the practice of gamete (egg and sperm) donation in the treatment of infertility have rarely been investigated (Skoog Svanberg *et al.*, 2003; Hudson *et al.*, 2009). Similarly, attitudes of clinic staff (gynaecologist, nurses and obstetricians) who are closely involved with the couple are poorly known (Skoog Svanberg *et al.*, 2008; Lampic and Skoog Svanberg, 2009). Limited research has focused on public perceptions of infertility treatment with donor gametes, and no data exist on public perceptions of gamete recipient families (Hudson *et al.*, 2009).

Secondly, very little is known about confrontation efficacy. Couples are often reported to feel insecure about how to discuss the topic with others, or to feel—later in life—incapable of telling the offspring. Group seminars have been reported to impact the level of confidence and ability to discuss the topic of (non-) disclosure (Daniels *et al.*, 2007). The same extent of impact may not be achieved by individual/couple counselling but further research is needed on this topic.

Thirdly, research on the influence and attitudes of extended family (grandparents, siblings) and friends on the disclosure decision is still very limited. Close relationships may feel trustworthy and are a source of support, but they can also pose a high risk of rejection. Knowledge on how 'family' is defined and experienced by extended family members is needed to better understand the impact of closeness in relationships.

Finally, apart from the above central factors which influence the disclosure decision, few data are available on how the disclosure decision is influenced by cross-border ART, culture (e.g. non-Western cultures, Western countries adhering to gamete donor anonymity), social class, education level and gender differences as regards the perception and coping of stigma on infertility and third party reproduction. In order to better understand (non-)disclosure decisions within the family unit, the impact of siblings with the same or a different donor and the offspring's gender on the creation of the 'family-formation story' needs further investigation.

Methodological features

More accurate information on regulations or clinic policies, the content and accessibility of counselling, participants' demographics, amount of donor information etc. is required to evaluate the impact of specific

factors on (non-)disclosure intention and behaviour, and to enhance comparison between studies. Moreover, reliance on only one information source (e.g. only mothers) or only one method of measurement should be avoided not only to enhance reliability but also because the disclosure decision in heterosexual couples is a decision that concerns, and should be made by, both partners (although couples are not always in agreement over disclosure, and one parent may disclose without the other parent's knowledge but this is separate issue). Also, more detailed information on interview topic-guides or questions is required to allow a better evaluation of data validity and to encourage methodological discussion.

Finally, almost all published studies are based on a 'one-point in time' design, despite the knowledge that the disclosure decision-making process can change over time. Therefore, research designs should incorporate this aspect of the disclosure decision by adopting a longitudinal design.

Conclusion

The aim of this review was to integrate the existing knowledge on factors that influence the parents' decision regarding disclosure of donor conception to offspring and/or to others. To integrate the influence of intra-personal, interpersonal, social and family lifecycle factors on the decision process, a theoretical model was highlighted. This emerging area of research is of considerable importance to public health policy and clinical practice in third party reproduction.

Authors' roles

A.I. did data extraction, critical appraisal, data analysis and interpretation and writing of the report. K.R.D. and T.D. did critical appraisal, data interpretation and supervision of the writing process. All authors approved the final version for submission.

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Conflict of interest

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