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Sperm donor conception and disclosure to children: a 10-year retrospective follow-up study of parental attitudes in one French center for the study and preservation of eggs and sperm (CECOS)

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Objective: To evaluate the percentage of parents in one French center for the study and preservation of eggs and sperm who disclose their use of donated spermatozoa to their children.

Design: A questionnaire survey of couples who had a child using donated spermatozoa.

Setting: University hospital laboratory.

Patient(s): One hundred five couples.

Intervention(s): Questionnaire sent by mail.

Main Outcome Measure(s): The percentage of parents who disclose their use of donated spermatozoa to their child.

Result(s): Among the 157 questionnaires sent, 105 couples answered, which corresponded to 138 children. There were 40 (38%) couples who had already disclosed the donor origin to their child and 65 (62%) who had not. Of the 40 couples who disclosed the donor origin, 37 (93%) had intended to do so before making use of assisted reproductive techniques (ART), but two (5%) had not wanted to do so before ART. Among the 65 couples who did not inform their child, 42 (65%) planned to inform their child soon, but 20 (31%) wanted to keep the sperm origin secret. Of the 20 couples who wanted to keep the origin secret, nine couples had told other persons about the gamete donation but had not informed their child and do not intend to inform their child in the future.

Conclusion(s): This first report about disclosure attitude in a large cohort of parents of donor-conceived offspring in France showed that most parents had already disclosed their use of donated spermatozoa to their children or intended to disclose it soon and had an attitude after birth consistent with their intentions prior to ART. (Fertil Steril® 2017;108:247–53. ©2017 by American Society for Reproductive Medicine.)

Key Words: Sperm donation, disclosure, offspring information, secret

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The practice of assisted reproductive techniques (ART) (1) using freshly donated spermatozoa has been known since the eighteenth century. ART with donated spermatozoa was developed in the 20th century thanks to the mastery of human spermatozoa freezing. In France, the first center for the study and preservation of eggs and sperm (centre d'étude et de conservation des oeufs et du sperme, or CECOS) was created in 1973 to supervise these practices with respect to three key principles: free, anonymous, and voluntary donations. The centers were designed to meet the reproductive needs of heterosexual couples consisting of a man and a woman. Thereafter, the three key principles were included in the first bioethics law of July 29, 1994, and these aspects remained unchanged in the revised bioethics laws of 2004 and 2011. The French bioethics law requires that all gamete recipients consent to ART using donated gametes in the presence of a judge or notary, to certify the filiation between the child to be born and his parents and to attest to the lack of filiation between the child and the donor. Nevertheless, the law says nothing about disclosure and does not impose anything on couples or medical teams about disclosure. Today, the 27 French CECOS centers constitute a network and are grouped into a French federation of centers with common practices. Since 1973, approximately 65,000 couples have undergone ART using donated spermatozoa, leading to approximately 50,000 births, corresponding to an average of 1,000 births per year.

In the 1970s, whether the use of donated spermatozoa would be disclosed to the child was not always discussed during the consultations between the CECOS team and the couples. Since the systematization of psychological interviews, this question is always raised with couples. Interviews with psychologists have been systematized since the 1980s. During these interviews, the two members of the couple may be questioned together or separately. Discussions are focused on the experience of infertility for each member of the couple and on how they have gone through their period of mourning for their fertility. Moreover, the level of information shared with others and the intentions of the couples to disclose their use of donated sperm to their child are always discussed. Therefore, the intentions of the patients to disclose or not their use of donated spermatozoa to their future child are systematically noted during the first consultations with the CECOS team. For practitioners across the CECOS network, it is clear that the proportion of couples who intend to disclose this information to their offspring has increased over the years, although no French prospective study has been published. The first data in this field were acquired from a study in which part of the cohort consisted of couples with a child born using ART with donated spermatozoa who wanted a second child (1). A questionnaire regarding information on the child was sent, and each member of the couples responded separately. One-half of the couples who answered had the intention to inform the child, and 30% did not plan to inform the child. A second study including 20 CECOS centers and 407 questionnaires from 201 couples, with questionnaires focused on the couples' intention to share the secret of conception, showed that 65% of couples had the intention to tell their children about their use of donated sperm (2). However,

beyond the intentions, we have very little data on the actual information that is communicated by the parents to their child after the child's birth.

We published a pilot study at our center (3) that focused on couples who had a child using ART with donated sperm and who clearly expressed their intention to inform their future child before the ART. For this first study, we did not call undecided couples or couples who intended to keep the donor origin secret during the first consultations with the CECOS team. Among 38 questionnaires sent after a first telephone agreement to participate to the study, 20 couples answered (52%). Among the 20 couples who answered, 14 couples (70%) had already disclosed the donor origin to their child, four had the intention to disclose the information in the near future, and two changed their opinion, expressing a desire to keep the details of the conception secret. This first study showed us that couples agreed to answer our questionnaire, that some couples changed their decision about disclosure after childbirth, and that support after birth is needed to help couples share information with their offspring. In the international literature about the matter of disclosure to offspring, the majority of European and international studies have shown that homo-/heterosexual couples and single women did not disclose their use of donated spermatozoa to their child at time of the survey. However, results vary according to the studies, countries, and type of recipients (heterosexual couples, homosexuals couples, or single women) (4–9). Over the recent decades, many studies have been conducted in countries where gamete donation follows rules that are different from those in France. In France, the specifications of sperm donation are that it is only available for heterosexual couples and that it is strictly anonymous. In this context, only two studies have attempted to evaluate the percentage of parents who disclosed the donor origin to their offspring, but the percentages were based on couples who answered the questionnaires, and there have been relatively low participation rates (1, 3). However, it seems that couples interviewed before ART are more open to disclosing the information than couples who already have a child (1).

We set up this study to evaluate the parents who had at least one child by sperm donation in our center and to determine the percentage of parents who disclose their use of donated spermatozoa to their child. Moreover, we intended to determine whether the parents' actions after childbirth were consistent with their intention before ART and if there was a consistency between disclosure to the child and disclosure to family or close friends. Couples were first contacted by phone, and a questionnaire was subsequently mailed to couples who agreed to participate in the study.

MATERIALS AND METHODS

Target Population

We identified 317 births resulting from ART with donated spermatozoa from our CECOS center in Marseilles from 2002 to 2012. At the time of the consultations with the medical team, all couples gave their written informed consent to be contacted again after childbirth. We first called 317

couples; the telephone number was wrong for 68 couples, and 85 did not respond to our voice messages. Finally, 164 couples answered our call, and we explained the study objectives; 157 agreed to participate, and seven refused. We sent 157 questionnaires by mail to ask the couples about their attitude and intention to inform their child. The questionnaires were sent between January and February 2014. The number of couples per year is detailed in [Table 1](#).

Survey

The questionnaire ([Supplemental Material](#)) included 20 items with open or closed questions and aimed to determine the following: [1] the percentage of parents who disclose their use of donated spermatozoa to their children; [2] whether the parents' disclosure was consistent with their original intention before undergoing ART; and [3] the circumstances under which and by whom the disclosure was made. The first part of the questionnaire ([Supplemental Material](#)) provided information regarding the person who completed the questionnaire and their child's birth year (questions 1 and 2). The second part (questions 3–5) asked whether close family or friends were informed about the use of donated spermatozoa, by whom the information was transmitted, and at what time with respect to the childbirth. The third part (questions 6–20) asked whether the information was disclosed to the child by the parents. Finally, a free response area was available to people who responded to the questionnaire.

Data Analysis

Each filled questionnaire was transcribed into an Excel file to confirm that each questionnaire was fully filled. Data collected in an open-response format were categorized according to content, which were agreed upon by the first author and the last author. No statistical tests were used because the comparison of subgroups was not the objective of the study. This study was approved by the local ethics committee and Institutional Review Board, the Comité de Protection des Personnes Sud Méditerranée I (reference RO-2016/43).

RESULTS

General Data

Among the 157 questionnaires sent, 107 couples answered (corresponding to a participation rate of 68%); 105 questionnaires were fully completed, corresponding to 105 pregnancies and 138 children born between 2002 and 2013 (no birthdate was specified for two children). Among the 105 couples, 72 had one child, 31 had two children (in separate pregnancies for 26 couples and twins for five couples), and two had three children (two separate pregnancies: one singleton and one twin). The majority of the questionnaires (71, or 67.5%) were filled out by the couple, 28 (26.5%) were completed by the mother alone, and six (6%) were completed by the father alone. The number of children born each year from 2002 to 2013 are reported in [Figure 1](#). As indicated, the birthdate was not specified for two children (1.5%).

The Disclosure to the Offspring: By Whom, When, in What Circumstances, and the Child's Reaction

Among the 105 couples who returned the questionnaire, 40 couples (38%) had already disclosed the donor origin to their child, and 65 (62%) had not. This corresponded to 59 (43%) children who were informed and 79 (57%) who were unaware of their origin. Of the 40 couples who informed their children, the information was disclosed to the child by the couple in 32 cases (80%) and by the mother in eight cases (20%). However, there were no cases where the father alone informed the child. Among the 59 children who had been informed, 18 children (30.5%) were informed from birth. In these cases parents simply began telling their young infants the story of their conception. The distribution of the 59 informed children according to the age of disclosure is summarized in [Figure 2](#). On average, the children were informed at 2.5 years. Children were mostly informed between birth and 6 years (70% between 0 and 3 years, and 95% between 0 and 6 years). Of the 40 couples who informed their children, 21 couples (52.5%) did it during the reading of a story, 13 (32.5%) during a discussion, five (12.5%) due to a child enquiring about the

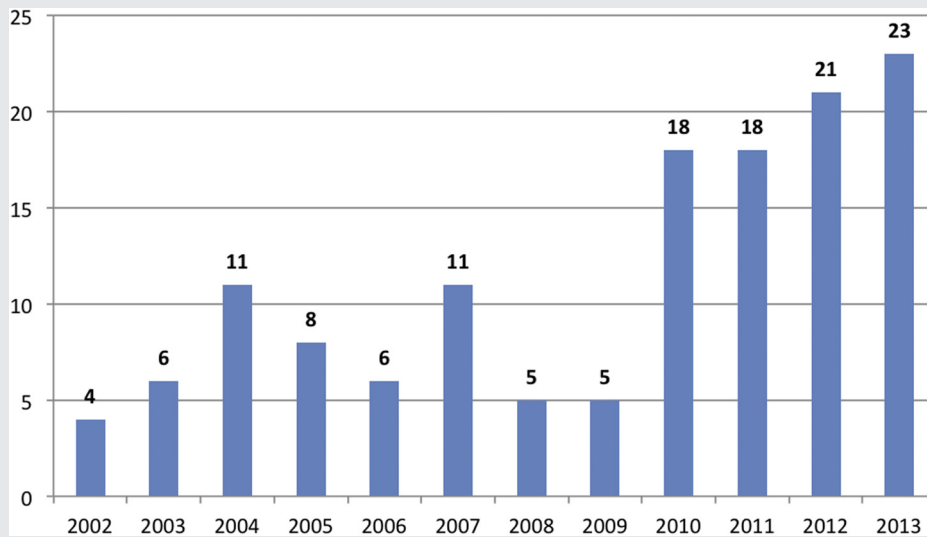
TABLE 1

Distribution of couples involved in the survey according to the year of pregnancy.

Year of pregnancy	Couples, n	Couples who agreed to participate, n	Couples who refused to participate	Invalid phone number, n	No response to the call, n
2002	29	6	0	12	11
2003	34	15	0	11	8
2004	25	11	0	9	5
2005	24	10	3	9	2
2006	21	9	0	5	7
2007	17	8	1	1	7
2008	16	5	0	3	8
2009	31	13	0	4	14
2010	45	30	1	8	6
2011	32	20	2	2	8
2012	43	30	0	4	9
Total, n (%)	317 (100)	157 (49.5)	7 (2)	68 (21.5)	85 (27)

Lassalède. French attitudes about donor disclosure. *Fertil Steril* 2017.

FIGURE 1



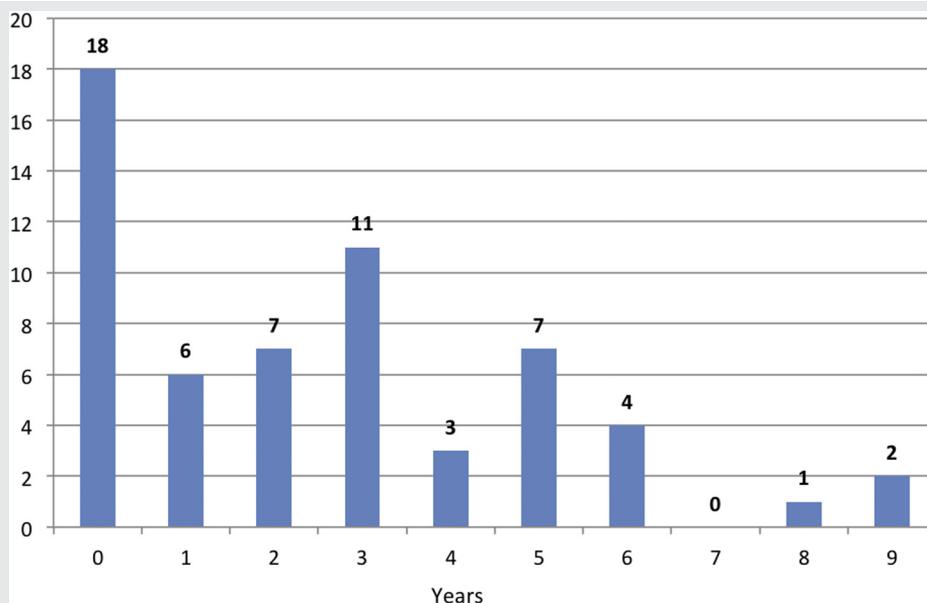
Distribution of the number of births for the 138 children born after ART with donated spermatozoa among couples who answered the questionnaire, per year between 2002 and 2013 (the birthdate was not specified for two children).

Lassalzedé. French attitudes about donor disclosure. *Fertil Steril* 2017.

terms of procreation, three (7.5%) during the course of having another child, three (7.5%) without specific reasons, and two (5%) due to the advice of a third person. Finally, two (5%) couples did not report the circumstances of the conception (nine couples gave two responses to this question). Among the 40 couples who informed their children, 31 (77.5%) used a visual medium to initiate the child's information or provide supple-

mentary information; the medium was either a book or a video. The nine other couples (22.5%) did not use any aids. Among the 59 informed children, 31 (52.5%) of them showed no reaction, 20 (34%) reacted well, three (5%) reacted with happiness, one reacted with sadness, and one reacted with difficulty. The reactions of three (5%) children were not specified.

FIGURE 2



Distribution of the 59 informed children according to the age of disclosure.

Lassalzedé. French attitudes about donor disclosure. *Fertil Steril* 2017.

Parents Who Did Not Disclose the Donor Origin to Their Child

This group represents 65 couples in our study. Their motivations were as follows (multiple answers were possible): 41 couples (63%) did not disclose due to the young age of the child; five (8%) expressed fear that the child would suffer upon learning this information; five (8%) wanted to keep the origin secret; four (6%) gave no explanation; three (5%) reported that the subject was painful for them; three (5%) expected that the child would broach the subject; three (5%) did not know how to begin the discussion; two (3%) did not disclose due to the father's refusal; one (1.5%) wished to gradually explain the circumstances of the conception to the child; and one (1.5%) stated that the stipulation regarding donor anonymity conflicts with the disclosure to the child. Two couples gave no explanation, and five couples gave two answers. Regarding the intention of these couples to disclose the information to their children in the future, 42 (65%) plan to inform later, 20 (31%) wish to keep the origin secret, and three couples (4%) did not answer this question. Among the 42 couples who intended to disclose later, they plan to do so when the child will be able to understand (nine couples, 21.5%), at a specific age (nine couples, 21.5%), or if the child asks (14 couples, 33%); some had no specific plan (10 couples, 24%). Among the 20 couples who intend to keep the donor origin secret, their motivations were as follows: to avoid child suffering (n = 5), by choice of the parents (answer given without other explanation, n = 5), to preserve the relationship between the father and child (n = 1), to avoid the couple's suffering (n = 1), due to the father's refusal (n = 1), due to anonymity (n = 1), and unspecified (n = 4). Two couples gave two answers.

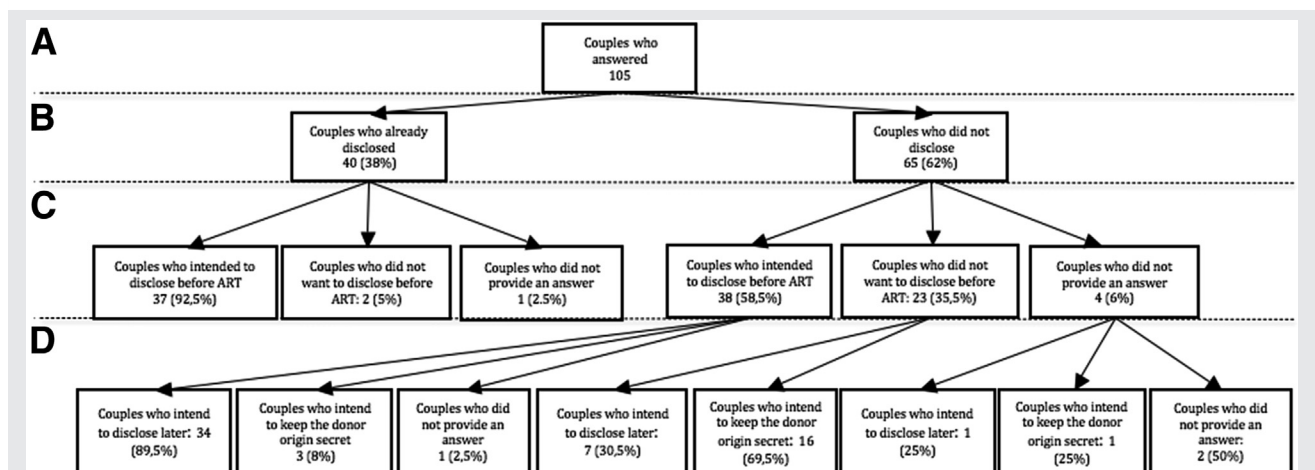
The Consistency of Couples Regarding the Decision to Disclose the Child's Information before and after Childbirth

Among the 40 couples who disclosed the donor origin to their child, 37 had planned to disclose before ART, and two couples disclosed although they did not intend to before ART. The reasons were a father's change of mind for one couple and a meeting with a psychologist for the other. One couple did not answer about what was planned before ART. Conversely, among the 20 couples who did not disclose and who certified that they wanted to keep the donor origin secret, 16 had planned to keep the origin secret before ART, and three said they were planning to disclose before the ART. The reasons for their attitude change were to protect the relationship between the father and child for two couples and to avoid suffering for the child for one couple. We also noted that among couples who had not disclosed the donor origin, seven of them wanted to do it later, even though they had not wanted to do it before ART (Fig. 3).

The Consistency Between the Disclosure of Donor Origin to the Child and to Other Persons

Among the 105 couples who returned the questionnaire, 89 (85%) answered that they had already disclosed the donor origin to other persons, and 16 (15%) reported not having done so. Of these 89 couples, most of them informed their family (86 couples, 97%), 63 informed their friends (71%), 20 informed their professional circle (22%), and six (7%) informed other people. Among the 89 couples, 74 (83%) disclosed the information before childbirth, 13 (15%) did so before and after the childbirth, and one (1%) did so only after childbirth. One couple (1%) did not answer this question.

FIGURE 3



Attitudes and intentions of couples after childbirth about offspring disclosure according to their intention before ART. (A) Respondents. (B) Parental action already taken at the time of the study. (C) Intend before ART. (D) Parental intentions after the study.

Concerning the consistency between the disclosure of donor origin to the child and to other persons, our data showed that of the 40 couples who informed the child, 39 also informed other persons, and one couple did not. Of the 65 couples who did not disclose the donor origin to their child, 50 of them had already informed other persons, and 15 did not. Among these 50 couples, 38 intend to inform the child later, whereas nine do not intend to inform their child later, and three did not specify their intention to inform their child later. Thus, nine couples are planning not to inform their children, despite the fact that others are aware of the use of donor sperm.

DISCUSSION

This study queried parents whose children were conceived through sperm donation to determine their opinions and attitudes about the disclosure of donor origin to their offspring. This is the first evaluation of the attitudes of parents who used donated sperm in France, a country where ART is reserved for heterosexual couples and where gamete donation is strictly anonymous according to the bioethics law. Considering the number of couples who agreed to participate during the phone call, we obtained a high participation rate of 68%. This is the first French monocentric study to collect evidence regarding three important points.

The main finding of this survey was that 38% of couples who responded to the questionnaire had already told their offspring about the donor conception. This seemed relatively high compared with the rates reported in several other studies of disclosure in heterosexual couples, which were less than or equal to 30% (10–12). However, the couples who responded were surely those who had less difficulty in sharing information about donor conception. Therefore, although there was a good participation rate, these responses did not allow for a reliable estimation of the number of children informed, although they certainly represent a first step toward this estimation.

The majority of parents in our study who had told their child had started to provide information at an early age, 2.5 years. Other studies have reported that a common age for disclosure was around age five, plus or minus a few months (7, 13, 14). In France, CECOS centers systematically invite couples before ART to be transparent about the donor conception to ensure balance and trust between the child and the parents. There is, however, no legal obligation. This attitude must be pursued, especially since a recent study showed that the earlier the children are told about their origin, the more positive the family relationships and psychological well-being at adolescence (15). Moreover, it must be noted that disclosure should not be seen as a single event but as an information-sharing process (16). In most cases, the information was mainly transmitted by the parents, sometimes by the mother alone, but never by the father alone. Among couples who informed the child, most used a support aid such as a book for the reading of a story, suggesting that support aids could be an effective and reassuring way for parents to discuss the subject with the child. In our survey, after disclosure, the children generally showed no response or re-

acted rather well, and the majority of the children did not show a negative reaction. This may be due to the young age of the children.

The second finding of this survey was that most couples had a consistent attitude after birth compared to their intentions before ART, but some parents changed their minds after childbirth. It is important and very interesting to note that the couples typically remained consistent between the first discussions in the CECOS center and the time after birth. This may indicate that the majority of those who replied had carefully considered the question of disclosure before ART. We, of course, cannot say anything about couples who did not answer after our first phone contact (18%), and we fear that the situation was not so clear for them. However, our survey showed that among couples who answered the questionnaire, a few had changed their minds about the disclosure. This change occurred in both directions: in favor of secrecy and in favor of disclosure. Regarding the former, the couples finally disclosed the donor origin because the father changed his mind and agreed to disclose or following an interview with a professional psychologist. This showed that parents can reach this decision with time and with the advice of a third party. Regarding the latter case, the couples opted for secrecy to avoid the suffering of the child or to protect the father. The parents' anxiety about the father's status and the fathers' fear of rejection has been reported by others (12). The choice of keeping the donor origin secret may be related to an identity-protection strategy that would protect both parents, especially the father, which reflects a form of parental vulnerability (17). It is clear that the decision to keep the donor conception secret depends on several factors, even in a country like France where ART using gamete donation is anonymous. Nonetheless, the change of opinion shows the importance of time in the parent's decision but also highlights the importance of follow-up for the couples as well as the importance of longitudinal prospective studies to evaluate the parents' medium- and long-term attitudes (17, 18).

Finally, our results clearly show that several parents had told other persons about the gamete donation but had not informed their child and do not intend to inform their child in the future, which is consistent with prior studies (4,13,19–21). Despite having informed close contacts, mainly family or close friends, several parents still decided to keep the donor origin secret from their offspring, taking the risk that the donor origin could be communicated by another person. It is therefore important for health care teams to inform couples about the potential difficulties generated by an incongruous situation where some members of the family's community are informed of the child's donor conception and the child is not.

The limitation of this study is that despite the high response rate, some parents did not participate or refused to participate in the survey. As previously reported (12), this population of parents might not be inclined to disclose the donor origin to their child. However, this survey provides evidence that some French parents of donor-conceived offspring actually disclose the donor origin during the first years of the child's life. In conclusion, the main strength of this work is that this is the first report about disclosure

attitude in a large cohort of parents of donor-conceived offspring in France. Nevertheless, further studies are required at the national level to assess the attitude of parents of donor-conceived offspring in France, especially, in a longitudinal and prospective way.

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