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# Strategies for disclosure: How parents approach telling their children that they were conceived with donor gametes

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# Abstract

**Objective**— To describe how parents envision, plan, and enact disclosing to their children that they were conceived with donor gametes.

**Design**— In depth ethnographic interviews.

**Setting**— Participants were recruited from 11 medical infertility practices and 1 sperm bank in Northern California.

**Patients**— 141 married couples who had conceived a child using donor gametes (62 with donor sperm and 79 with donor oocytes).

Interventions— Husbands and wives were interviewed together and separately.

Main outcome measures— Thematic analysis of interview transcripts.

**Results**— Disclosing parents predominantly subscribed to one of two disclosure strategies: the conviction that early disclosure is of paramount importance so that the child "always knows," or the belief that later disclosure is preferable after family routines have been established and the child has the maturity to understand biologic concepts and has developed a sense of discretion. No parent regretted disclosing and many expressed relief.

**Conclusions**— Parents choosing early disclosure were more at ease with the disclosure process while parents choosing later disclosure reported greater uncertainty about how and when to disclose. Parents wished for more peer and/or professional support and guidance to assist them in with disclosure, not only initially, but continuing long after their children are born.

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Parents generally employed either an earlier ("seed-planting") or later ("right-time") disclosure strategy in telling or planning to tell their children that they were conceived with donor gametes.

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#### Keywords

egg donation; donor insemination; donor conception; disclosure; strategies; infertility; origin narratives; scripts; support; counseling

#### Introduction

Although donor insemination (DI) has been widely practiced for decades and conception following egg donation (ED) has been available for over twenty years, whether parents who conceive with donor gametes should reveal this fact to their children is still the subject of ongoing commentary by physicians, psychologists, social workers, ethicists, parents, and donor offspring. Medical practices, legal requirements, and control and supervision of gamete donation by regulatory agencies vary dramatically around the world, reflecting this lack of consensus. For example, policies that support non-disclosure have been legislated in France, Denmark, Spain, and Norway, while policies favoring disclosure have been established in Sweden, Austria, Switzerland, Netherlands, and the Australian State of Victoria.

Although past research has shown that the majority of parents who conceived with DI elected not to disclose these facts to their children (1–10), some authors maintain that there may be an increasing trend for parents to favor disclosure (11–14), a stance recently supported in guidelines encouraging disclosure published by the American Society for Reproductive Medicine's Ethics Committee (15). While considerable research has addressed parents' motivations for disclosing or not disclosing their use of donor gametes to offspring (1,3,7,10, 14,16–19), with few exceptions (7,18–20), there has been little exploration of the manner in which parents actually envision and enact disclosure. By reporting the findings of a large qualitative interview study examining DI and ED parents' experiences with disclosure, we hope to add to the current understanding of parents' disclosure planning, timing, and the specific strategies and narratives they utilize for conveying this information to their children.

## Methods

Participating couples were recruited from 11 medical infertility practices and 1 sperm bank located in four counties in Northern California. Practitioners sent a letter introducing the study to their former patients. Couples who were interested in receiving additional information about the research returned a stamped, addressed postcard to the investigators stating their willingness to be contacted. To be eligible for selection, the couple or individual had to have been in a heterosexual marital relationship when one or more living children were conceived with the use of donor gametes. The study protocol and consent form were approved by the Committee on Human Research, the Institutional Review Board of the University of California, San Francisco.

The interviews were conducted by seven members of the research team who were trained in ethnographic interview methodology. An initial interview with the couple was followed by solo interviews with each partner separately approximately three months later. If one but not both members of a couple agreed to be interviewed, those individuals were also interviewed. The one to two-hour long interviews were semi-structured with open-ended questions that focused on disclosure and related topics that included the couples' philosophy of family, family relationships, feelings about having used a donor, and approaches taken to telling their children. These interviews were tape recorded and transcribed verbatim.

Transcripts were numbered and identified as to whether the children were conceived using donor insemination or egg donation and by the disclosure decision that the couple had reached

at the time of the final interview. Disclosure meant disclosing to the child: couples were categorized as disclosers (those who reported they had already disclosed or had begun to disclose), non-disclosers (those who did not plan to disclose), plans to disclose (those who had not yet disclosed but planned to at some future date), or undecided.

Themes that appeared in the data were identified, and codes defining and referencing these themes were developed. Each code was a key word or phrase identifying an idea, theme or concept. Each paragraph of each interview transcript was then analyzed for its thematic content and assigned one or more of these codes. By entering the coded interview transcripts into QSR International's NUD\*IST data sorting program, all interview data relating to any specific coded theme could be subsequently retrieved for further analysis. This paper is based on an analysis of the interview data identified by the codes "tell child" and "tell plan."

The "tell child" code was defined as "statements referring to feelings about or the experience of disclosing or not disclosing to child, including anticipation of child's response and the ongoing influence on the couple relationship and anticipated parent-child relationship." The "tell plan" code was defined as "statements referring to an imagined or actual scenario, plan, or approach used to disclose; decisions about when to tell; narrative, plan, or books used to explain gamete donation to child." Finally, the coded excerpts were cross-checked by reading the transcripts from which they had been identified to confirm that excerpts were not misinterpreted by being read out of context.

### Results

#### **Participant Demographics**

The total study sample was comprised of 141 couples: 62 couples who conceived with donor insemination and 79 couples who conceived using egg donation. Of the DI couples, 20 (32%) had already disclosed, 28 (45%) planned to disclose, 10 (16%) did not plan to disclose, and 4 (6%) were undecided. Of the ED couples, 18 (23%) had already disclosed, 46 (58%) planned to disclose, 8 (10%) did not plan to disclose, and 7 (9%) were undecided. As this paper focuses exclusively on the strategies and methods of disclosure, the findings are based only on interviews with the 112 families (48 DI, 64 ED) who disclosed or planned to disclose and excludes the remaining sample of non-disclosing and undecided parents. We found no differences between how those who have disclosed and those who intend to disclose described their strategies for and their feelings about disclosure.

The demographics of the disclosing sample of these 112 couples did not differ meaningfully in any of the demographic categories from those of the total sample and are presented in Table 1. This sample is made up of predominantly Caucasian, highly educated, affluent professionals. There was no major difference between DI and ED couples with respect to gender, ethnicity, occupational status, or number of donor-conceived children. We did find that ED families had a slightly higher median household income and educational level than DI families. For disclosing ED families, the average age of the oldest donor-conceived child was 3.5 years, whereas for disclosing DI families the average age of the oldest donor-conceived child was 7.2 years.

#### **Disclosure Strategies**

We found that many parents who had disclosed or who planned to disclose experienced varying degrees of uncertainty about how their children would react and what effect the disclosure would have on the family. These parents voiced a variety of concerns that included worry about being rejected by their children, losing the trust of their children, having their children's emotional development or behavior be disrupted by either the fact of donor conception or how

the disclosure information was conveyed, or having their children experience stigma, either from third parties outside the immediate family or by the children comparing themselves negatively to other children and families. Despite these concerns, these parents articulated a commitment to disclosure and expressed the desire to create and maintain strong and trusting relationships with their children that could withstand the disclosure, to present the donor information in a positive or neutral way, and to enact the disclosure at such a time and in such a manner that would be least disruptive to the child's development and family cohesion.

We found that both DI and ED parents employed one of two plans or strategies to tell their children that they were conceived with donor gametes. These differ in several aspects of their timing and the actual manner and process of disclosure. We refer to these strategies as "seed-planting" and the "right-time." These strategies were usually used alone, but sometimes in combination. Specifically, of the 38 couples who had already disclosed, approximately two thirds employed the seed-planting strategy, approximately one quarter employed the right-time strategy, and the remainder employed a combination of elements from each. Of the 74 couples who intend to disclose, approximately one quarter indicated they will employ the seed-planting strategy, approximately one half indicated they will employ the right-time strategy, and approximately one quarter indicated they will use a combination of both.

#### Seed-planting strategy

The seed-planting strategy is distinguished by the conviction that early disclosure to the child is of paramount importance. Parents who employed the seed-planting strategy voiced the opinion that, because the child would have "always known" the information about their conception from his or her earliest recollection, there would be no time where it would be necessary to "sit down and have this [disclosure] discussion." Parents felt that having the child "always know" about their donor conception prevented the possibility that the information could result in a break in trust with the child because the parents "waited too long" to tell, especially as these parents believed that postponing disclosure to an older child could be perceived as concealing information and could signal that donor conception was something "weird," shameful, or out of the ordinary. By presenting the donor conception in a "natural" and "matter of fact" manner, parents believed it would become "no big deal." Furthermore, casual and recurring sharing of the information within the context of regular family activities would reinforce the message that the use of donor gametes was not outside the scope of normal family life.

The seed-planting strategy was typically initiated when the child was between ages three and four, beginning when the child asked basic origin questions such as "Where do babies come from?" or "Did I grow in your tummy?" A minority of parents began to disclose to their children prior to the children asking questions or when the children were pre-verbal in order to "practice" or "get used to using the words." A few parents were disappointed when they perceived little or no feedback after attempting to disclose to their very young children. This lack of response led them to postpone disclosure and resume the discussion when they felt the children could better understand the information.

Seed-planting disclosure was carried out by one or both parents, although more frequently by mothers, and was often performed on an ad hoc basis in the course of daily life. Parents anticipated that the questions the children asked, with whom they chose to share the information, and how the children responded to the information would influence how the disclosure unfolded. Parents sought or planned to seek opportunities to discuss the use of donor gametes with their children so that, through repetition and positive reinforcement, the information would become routine and be "part of the fabric of their lives."

#### **Right-time strategy**

The right-time strategy is characterized by the belief that there is an optimal time or "window of opportunity" in the child's development during which he or she is best able to receive and comprehend the disclosure information. In contrast to the seed-planting strategy where the story unfolds incrementally from an early age, parents using the right-time strategy thought of the initial disclosure as a singular event. Although many reported that there was an intuitive aspect to the right-time criteria (i.e., they would "just know" when the time had arrived), some parents identified factors that contributed to their understanding of when that "right-time" emerged. In general, parents foresaw the right time as beginning when their children developed the cognitive skills to understand the medical and technical nature of the procedures, but ending before adolescence. Because parents choosing the right-time approach often expressed the belief that disclosure would be meaningless to children who could not grasp the biological details of reproduction, many expected that disclosure would coincide with a discussion about sex or "the birds and the bees talk." Although parents who intended to disclose often projected this time to be approximately between the ages ten and twelve when children receive sex education in schools, we found that parents using the right-time strategy who had already initiated disclosure actually began between the ages of six and seven.

A second element characterizing the right-time strategy was the concern that disclosing too early could result in the child being "confused," "upset," or "alienated." To address this concern, parents viewed the years leading up to disclosure as an opportunity to establish "normal," "familiar," and "loving" family routines that would allow the parent-child relationship to develop unhindered by the donor information. For example, as one DI mother put it, "I don't want to make him deal with something adult too soon." This trust-building period was also seen as valuable in preempting the potential for post-disclosure rejection of the parents by the children, particularly the non-gamete-contributing parent. For example, as one DI father said, "it was a good decision to tell them when they knew our relationship was strong."

Finally, right-time strategists reported that their children's personalities and maturity influenced the timing of disclosure. For example, some parents waited until they perceived their child was emotionally able to "handle" the information. Others felt that a prerequisite to disclosure was that the child have discretion and be able to understand the concept of public and private information. However, some were more fatalistic about the timing and felt that they would disclose and "then deal with it after that, all the emotions and whatever needs to be dealt with ...."

In addition to the "right time," parents employing this strategy frequently felt that it was important for them to identify the "right way" to inform their children about their donor origins. In the right-time strategy, disclosure was envisioned as a specific and special event that took place outside of the context of routine family activity. Typically both parents were present and the child was told specific details of the donor procedure. Yet parents using the right-time strategy expressed more uncertainty about the disclosure process and outcome than did those employing seed-planting. Many parents expected that their children might question them as to why they had used donor gametes, and some anticipated judgment or criticism from their children for using a donor or for their choice of the particular donor.

In the face of this uncertainty, parents using the right-time strategy frequently articulated a desire for guidance and advice. Parents' specific requests for assistance included written or online resources, subject-specific counseling, and especially peer information and anecdotes to help them with disclosure. Many parents not only wanted help in choosing the words to say to their children but wished for a menu of options to choose from when disclosing. Optimally,

this menu would not only include advice on timing and disclosure scripts, but would also provide evidence about the efficacy and impact of each disclosure option.

#### **Disclosure Language and Narratives**

Regardless of their disclosure strategy, many couples found it not only challenging to identify exactly what they might say to their children, but they were frustrated in their attempts to find comfortable language with which to discuss the use of a donor. Parents reported that what was important for them was to describe the biological nature of the children's origins while clearly conveying their own social primacy. As one DI husband put it, "...what I am looking for is a way for him to be able to process the information without being told that I'm not his real father." Many suggested that they "would like help with developing a vocabulary," particularly with respect to their need to refer to the gamete donor without confusing the role of the donor with the roles of other family members, as most parents found themselves interchangeably describing themselves and the donors as "parents," "biological parents," "genetic parents," and "real parents." Yet most DI and ED parents anticipated being upset or "devastated" if their children were to say to them "you are not my real mother" or "real father."

We found that the seed-planting and right-time strategies drew on several common themes and narratives to enact disclosure. The children's ages at the time of disclosure or the time when disclosure was envisioned to take place influenced which themes were emphasized. In general, parents employing the seed-planting strategy described using "simple" or "age-appropriate" language with younger children that would become more sophisticated as the child developed. These parents frequently described providing measured amounts of information and avoided sharing more that the child could receive in the context of the moment. On the other hand, right-time strategists used or envisioned using detailed language to describe the procedural aspects of donor conception to their children, requiring greater capacity by the children to comprehend more complex information.

We found that parents subscribing to both seed-planting and the right-time strategies employed one or more of five narratives/themes/stories to tell (or plan to tell) their children about their donor conception. We have identified these narratives as 1) "the helper," 2) "spare parts," 3) "families are different," 4) "labor of love," and 5) "nut and bolts." These narratives were frequently used in combination or in succession whereby parents began with simpler themes and added more complex elements to the stories as the children grew older. Both DI and ED parents used these stories, although DI parents gravitated toward a "spare parts" narrative whereas ED parents tended to favor the donor version of the "helper" story.

In "the helper" story, parents conveyed the idea that they needed assistance to have a baby and that "someone helped us to have you." This assistance was provided by a donor, a doctor, or both. Where the helper was the donor, he or she was presented positively as a "special" or "nice" person or a "friend" and the donor was often described as having provided a "gift" to the parents. In another version of this narrative, the doctor is described as the "helper." Typically parents said "a doctor helped us to have you." Some parents used elements of both helper stories, for example, "a nice person gave us sperm (or eggs) and a doctor helped us to have you."

The "spare parts" narrative expressed the idea that the non-gamete contributing parent had a "missing" or "broken" part that needed replacing in order to have a baby. Sometimes parents emphasized that their bodies "worked differently" than other people's. "Spare parts" were provided by doctors or by other people. For example, one couple told their DI child that "daddy's sperm was broken, so we got sperm from a doctor," while another couple said "we got medicine from a doctor."

"Families are different" is a story in which the donor conception is set within the context of a multiplicity of family building techniques. Parents typically conveyed or anticipated conveying to children that there are many ways to make a family and their particular choice was to use a donor. In comparison to families created with donor gametes, other family descriptions included those with adopted children, step-children, single parents, gay or lesbian parents, and bi-racial families. We found that parents using the seed-planting strategy were much more likely to reference similarities between donor disclosure and telling children that they were adopted than were those employing the right-time strategy. Some parents reported using or being interested in using children's books to convey this message and/or as a launching point for disclosure.

Parents, particularly those who had not yet disclosed, often described the "labor of love" theme by which they conveyed or hoped to convey to the children how much they were wanted. In these stories, their decision to choose donor conception was portrayed as being motivated by a great love and desire to have their children. This narrative could take two subtly different forms. In the first version, parents expressed the idea that they wanted their children "so badly" and they "love them so much" that they did what was required to have them, implying that they really had very little choice. In the second version, parents expressed that they wanted their children so badly that they "worked so hard" and went to great lengths to have them, implying a sense of sacrifice via their "hard work" or "struggle" to have children.

Some parents who had yet to disclose only envisioned describing the technical details or "nuts and bolts" of the donor conception to their children. This approach assumed that the child would have a certain knowledge and maturity level to be able to understand reproductive concepts. For example, some parents envisioned saying "we used a donor's sperm" or "a donor egg" "which was placed inside mommy and then you grew."

Finally, most parents said that they had difficulty finding resources to assist them in disclosing. While some looked to children's books for assistance, others found that the books did not address their specific situation or match the developmental level of the child at the time the parents wished to begin disclosing. Some looked to the fertility clinic or counselors for guidance, but several felt that IVF Clinics and infertility support groups such as RESOLVE were too pregnancy-oriented. Some sought "definitive answers" about what to say to their children or that they would "like someone to tell me what to say," while many said that they "would like to talk to others that have actually gone through this experience to find out what worked." Although couples greatly valued peer support, they had difficultly finding other parents in similar situations with whom to discuss the experience of disclosure.

#### **Disclosure Outcomes**

Whether using the right-time or seed-planting strategy, we found that women preferred disclosing to children at an earlier age than did men and in general were more concerned about waiting too long to initiate disclosure. We also found that men envisioned disclosure as conveying specific and technical details of the donor conception, while women considered a wider variety of information to be part of the disclosure process. Yet parents using both strategies were essentially unanimous in the belief that disclosure should occur prior to (or, in a few cases, long after) the onset of adolescence. Adolescence was described as a time when the children would be unreceptive to their parents and that disclosing during such an unpredictable time in the parent/child relationship was to be avoided.

Although parents reported a variety of feelings after disclosing that ranged from neutral to a profound sense of relief, no parent expressed regret or reported a negative outcome after having initiated disclosure. In most cases, parents reported that their children had no visible reaction or "took the information in stride." In several cases, the children asked clarifying questions,

and in a few others, the children did express sadness or asked "so does this mean you are not my real mother?" or "father?" However, even these parents told us that they did not feel the impact of these statements as negatively as they had feared, while parents who had reported feeling uncertainty prior to disclosing expressed sentiments of relief such as "that was pretty easy" and "the only one with difficulty with it was us, stumbling around." Although parents using the seed-planting strategy consistently described anticipating that disclosure would be an ongoing process, parents using the right-time strategy who had disclosed also acknowledged that disclosing would require ongoing conversations and would not be just a single event as they had originally envisioned.

## Discussion

It is well established that parents who conceive children using donor gametes find coming to a disclosure decision a challenging task, yet even those parents who have made a commitment to disclosure are frequently uncertain about the timing, the method, and the outcomes of disclosing (2,12,16–20). Based on in-depth interviews with 112 disclosing couples who had used egg donation or donor insemination to conceive at least one living child, this report summarizes our findings with respect to disclosure planning and timing as well as the specific strategies and stories parents utilize in conveying the disclosure information to their children. Although we originally anticipated that there might be qualitative differences in the attitudes of DI and ED parents, our finding that these parents voiced similar concerns and feelings about disclosure is supported by recent research by Kirkman in Australia and Golombok in Great Britain. (14,20,21).

We found that, despite their decision to disclose, parents of children conceived with donor gametes voiced a variety of concerns that have been consistently attributed to gamete donor parents in past research (1,3,7,10,14,16–20). As we found that both DI and ED parents typically employed one of two disclosure strategies to prepare for and enact disclosure to their children, we postulate that these strategies provide a framework for addressing their concerns and help parents manage their uncertainty while still retaining their commitment to disclosure. We refer to these strategies as "seed-planting" (distinguished by the conviction that early disclosure to the child is of paramount importance) and the "right-time"(characterized by the belief that there is a variably-determined, usually later time, when the child will be most receptive to disclosure, normalize the use of donor gametes, and address parents' fears and concerns about the impact of the information on the child and on the family.

Parents using a seed-planting strategy expressed the desire to normalize their use of donor gametes and to prevent a rupture in the parent-child relationships by disclosing early and often so that the children would "always know" and the information would be "no big deal." This strategy tacitly argues that if the donor conception is viewed as an integral part of the child's life history, there can be no time at which this information could significantly alter the child's relationship with the parents, thus avoiding the possibility of rejection or re-conceptualization. Overall, parents using a seed-planting strategy were more at ease with their disclosure decision and viewed disclosure as an ongoing process that would continue regularly until the parents felt that their children could recall and understand the information. These parents anticipated that their children's' responses would influence how the disclosure unfolds and indicated that they viewed the child as a participant in an evolving and interactive family narrative.

On the other hand, parents using the right-time strategy expressed a greater level of uncertainty about their disclosure plans and more concern about how the children would react than did seed-planting parents. Although parents using the right-time strategy also wanted to normalize the use of donor gametes and frame it positively, many viewed disclosure as precarious and

Parents using the right-time strategy envisioned the years prior to disclosure as a time that enables the establishment of relationships, routines and behaviors that represent stability and normalcy to the child. These routines are believed to not only reinforce trust among immediate and extended family members, but by allowing the child to mature for several years without being influenced or defined by the donor conception, stigmatizing messages from inside or outside the family could also be avoided. Furthermore, that parents using the right-time strategy expressed a concern with getting disclosure "right" may also reflect parents' fears about judgment or criticism from their children for having used a donor. As a result, right-time parents' attitudes suggested that the act of disclosure would be more like a performance enacted before the children by the parents, rather than the more interactive process favored by seedplanters. Because this desire for relative confidentiality and concern with preventing a disruption in parent-child relationships is strongly reminiscent of past non-disclosing attitudes that served to protect the family against the threat of social stigma (16), we conjecture that parents advocating a right-time strategy may represent a transition from past attitudes favoring non-disclosure toward a more current environment encouraging openness. On the other hand, the parental belief in the importance of having children be mature enough to grasp the details of reproduction is supported by the suggestion that children under the age of seven may not be able to comprehend the concept of biological inheritance that would contribute to an understanding of donor conception (22).

We found that most parents using the seed-planting strategy began or planned to begin disclosing to their children between the ages of three and four, coinciding with reports of early disclosure from New Zealand and the United Kingdom (7,14,17,19). Although parents subscribing to the right-time strategy anticipated disclosing to their children around the ages of ten to twelve, disclosure actually took place between the ages of 6 and 7, congruent with Durna's report of Australian DI parents planning to disclose to children age 8.4 years but actually disclosing to children at age 6.3 years (4). Finally, we not only found support for the observation that parents almost universally believe that disclosure should be avoided during adolescence (19), but very few of the parents in our study planned to disclose to post-adolescent or adult children.

While some researchers report that women tend toward greater openness than men with regard to disclosure (3,5,23-26), others have found no differences between men and women (7,10,27). We found that, in general, women were more likely to prefer to disclose earlier in the child's life than do men. In couples using the seed-planting strategy, mothers were more likely to be the parent initiating ad hoc disclosure, perhaps reflecting a greater amount of time spent with younger children. Finally, women considered general, less detailed conversations to be part of the disclosure process while men often thought that only the transmission of the specific details about the donor conception constituted disclosure. Past research citing gender differences was primarily conducted with DI families where it may be difficult to determine if approaches to disclosure differ between spouses because of gender differences or because of differences in the contribution of gametes; for example, Daniels suggests that in DI couples women defer to men's feelings about disclosure (25). Noting that approximately a quarter of our study's parents used a combination of disclosure strategies, we conjecture that when couples were undecided due to differences of opinion, compromise was perhaps reached by combining elements of the strategies where some information was shared early and more detailed information was reserved for "the right time."

Most parents expressed frustration with the perceived lack of comfortable language and "scripts" available to discuss donor conception with their children, especially as they struggled to find unambiguous terminology with which to refer to the donor, a difficulty also reported by Kirkman in interviews with 32 Australian parents (20) and by Scheib in a study of 45 American DI families (28). However, we were able to identify five different origin narratives that were used singly or in combination as the children got older, i.e., "the helper," "spare parts," "families are different," "labor of love," and "nut and bolts." There are considerable similarities between these origin stories and the disclosure themes reported by Rumball and Adair in New Zealand DI parents (especially with respect to the "helper," "spare parts," and "labor of love" narratives (7)) as well as overlap with Lycett's findings on English DI parents with respect to the "spare parts" narrative (19). These authors also found that parents gradually introduced the donor information, building on the story over time as children were better able to understand (7,19).

We conclude that these disclosure narratives presented the donor conception in a manner that normalized the use of donor gametes, minimized the importance of the actual donor, and protected their legitimacy in their social role as the "real" parents. The ages of the children at the time of disclosure and the parents' disclosure strategy appeared to be the most meaningful factors for parents in choosing among the disclosure narratives. Because early disclosure was initiated by conveying conceptual information to young children who would not grasp technical details, parents using seed-planting were faced early on with presenting the social implications of having used a donor, such as the donor's relationship to the child. On the other hand, because right-time disclosure was initiated later when older children were likely to have already established expectations of family roles, these parents chose to focus on conveying the medical details of the conception while minimizing discussion of the donor and emphasizing existing definitions of family.

For example, we found that although both DI and ED parents used or planned to use similar vocabulary and origin stories, DI parents used a "spare parts" narrative more often and ED parents favored the donor version of the "helper" story. This may also reflect DI's more depersonalized donor selection process where donors are largely anonymous and sperm is provided by commercial sperm banks. The physically innocuous nature of the sperm donation procedure may also make sperm donation seem more like just providing a "spare part," a theme which later is conveyed to the children.

In contrast, photos of egg donors are widely available and recipients may have the option to meet donors in person. In addition, the fact that the donor and recipient are undergoing simultaneous treatment in the same medical facility calls greater attention to the physical role of the donor, even when the egg donor remains anonymous. As a result, ED parents may favor origin narratives that are more inclusive of the donor because they may be more aware of the donor's presence and may have spent more time thinking about and imagining the donor. The greater invasiveness and risk involved in egg donation as compared to sperm donation may also make the "helper-donor" story more appropriate for egg rather than sperm donors. Finally, the differences between disclosure narratives of ED and DI parents may not only be based on gender distinctions inherent in the two procedures, but also upon their varied historical contexts.

The "helper-donor" story also serves to reinforce the primacy of the parents' relationship with the children while also acknowledging that another person was instrumental in creating the family. Hahn and Craft-Rosenberg (18) found that parents generally desired to place the donor in positive light, and Inhorn and Tober have also described the transaction as the donor providing a "gift" to the parents (29,30). Furthermore, recognizing the donor creates the possibility that some relationship may exist between the donor, the parents, and potentially the

children. On the other hand, in the "helper-doctor" and "spare parts" narratives, emphasis is placed on the parents' need for a solution or treatment for their problems having a baby, but the gamete contribution is depersonalized or characterized as a transaction or professional service rather than a gift exchange, and there is no implication of the possibility for an ongoing relationship outside the immediate family.

The "families are different" narrative depends on children being exposed to diverse family configurations, either in their own communities or through books and other media. This story not only demonstrates that the parents' choice was an active and purposeful one, but it also may serve to reduce a sense of "otherness" for the offspring conceived with donor gametes by fostering a sense of commonality with children and families created in different ways.

The "labor of love" narratives primarily addressed parents' motivations for using a donor and appeared to be positioned defensively, assuming or pre-empting a negative response by the children to disclosure. Parents employing the right-time strategy frequently invoked the labor-of love story in conjunction with a logistical explanation of the donor conception. This suggests that in some cases they were motivated by the hope that if the child knows how badly they were wanted they would have a greater appreciation and acceptance of the parents' decision to use a donor.

Finally, the "nuts and bolts" narrative, primarily employed by parents using or planning to use the right-time strategy, serves to convey scientific and medical details of the donor conception without addressing the possible social implications. Similar to the "spare parts" narrative, it highlights the procedural aspects of using donor gametes without overtly challenging the existing definition or experience of family that has already been presented to the children.

We found that the majority of DI and ED parents in this study had disclosed (32%) or planned to (45%) disclose to their children. Although these rates are higher than in most past studies on DI families (2,9,16), they are comparable to more recent studies of DI and ED families in Great Britain and Australia (7,14,18). The average age of the first-born donor-conceived child was a little over 5 years with both parents in their mid-to-late forties, primarily Caucasian, married, highly educated, and affluent – a demographic composition comparable to those reported in other recent studies on gamete donation families (10,18,31). Although a large number of gamete donor parents were interviewed, we acknowledge that our findings cannot help but be influenced by the self-selected nature of our study population and the fact that they reside in the affluent and politically and culturally liberal environment of Northern California.

There has been speculation that parents who plan to disclose but do not disclose early in their children's lives may ultimately not disclose at all. Several studies have found that most parents who planned to disclose to their children had not yet done so by the time the children approached age eight (1,4,5,10,23,24,32) and that disclosing becomes more infrequent as children age (4). As most of the donor-conceived children in this and other studies are relatively young, reports on final disclosure stances from non-longitudinal studies are likely to be inconclusive. The few longitudinal studies which have included children approaching adolescence found that most parents have not disclosed to their children (9,33,34). We cannot predict if the parents in this study who planned to disclose will follow through with their plan. However, we found no differences between how those who have disclosure and those who intend to disclose described their strategies for and their feelings about disclosure and their current or former uncertainties about the outcomes, with the one exception that many who had disclosed experienced relief.

We found that no parents regretted disclosing and most reported either a neutral or positive response from their children, congruent with other studies where parent's disclosure outcomes are available (4,7,19,28,34–37). Many parents in our study expressed relief after disclosure,

which we attribute to the absence of negative responses from the children. Although essentially all disclosing parents cited honesty as at least partial motivation for disclosing, those choosing the seed-planting strategy were able to act in concert with this belief early on, whereas those using the right-time strategy spent a number of years living somewhat at odds with their values. This tension is one that may contribute to right-time parents' greater uncertainty and discomfort prior to disclosing. Indeed, not only was the apprehension expressed by pre-disclosure parents far greater than those who had disclosed, but parents' fears about disclosure having a negative impact, at least initially, appear to be exaggerated.

Although couples may not follow the advice of counselors regarding disclosure (3-5,7,9,38-41), our findings support the long-standing observation that parents desire peer and professional help with disclosure (1,7,12,18,42,43) if only to help them formulate their own views. As it has been speculated that the general lack of assistance, and specifically the lack of disclosure "scripts" may be a deterrent for parents in carrying through with the disclosure (1), it seems clear that if disclosure of donor gametes is to become more widespread, parents will require greater support services to assist them in this process. Although Hunter and Lycett in Great Britain (17,19) and Rumball and Adair in New Zealand (7) reported wide use of written materials including "My Story" (44) and other similar books published in Europe and Australia, parents in this study, particularly those using the right-time strategy, generally expressed frustration at what they perceived to be a lack of resources and support to help them explain donor conception to their children. Whether this reflects a level of ambivalence, initiative, or motivation on the part of these parents or rather represents a lack of availability or guidance, it appears that many of these affluent and highly educated American men and women were not accessing or utilizing existing materials to assist them with disclosure. We did find that couples using a seed-planting strategy were more likely to embrace ideas and techniques commonly studied and used in adoption literature, which in turn may have contributed to their expressing a greater feeling of confidence than those using the right-time strategy.

Finally, we found support for the observation that disclosure is seen as an ongoing process by parents once it has been initiated (7,13,19,45). As such, we strongly agree with the suggestion that if there is indeed a shift toward greater openness in parents using third party reproduction, there will be an increasing need for support services to assist parents in this process not only initially, but continuing long after their children are born (1,2,10,14,20,28). Our belief is that support that parents will find most effective will be based on evidence from the experiences of other donor gamete families and will require continued research on the long-term experience of disclosing donor conception to children.

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#### References

- Cook R, Golombok S, Bish A, Murray C. Disclosure of donor insemination: parental attitudes. Am J Orthopsychiatry 1995;65:549–59. [PubMed: 8561188]
- 2. Brewaeys A. Donor insemination, the impact on family and child development. J Psychosom Obstet Gynaecol 1996;17:1–13. [PubMed: 8860881]
- Brewaeys A, Golombok S, Naaktgeboren N, de Bruyn JK, van Hall EV. Donor insemination: Dutch parents' opinions about confidentiality and donor anonymity and the emotional adjustment of their children. Hum Reprod 1997;12:1591–7. [PubMed: 9262303]

- Durna EM, Bebe J, Steigrad SJ, Leader LR, Garrett DG. Donor insemination: attitudes of parents towards disclosure. Med J Aust 1997;167:256–9. [PubMed: 9315013]
- Leiblum SR, Aviv AL. Disclosure issues and decisions of couples who conceived via donor insemination. J Psychosom Obstet Gynaecol 1997;18:292–300. [PubMed: 9443140]
- Nachtigall RD, Tschann JM, Quiroga SS, Pitcher L, Becker G. Stigma, disclosure, and family functioning among parents of children conceived through donor insemination. Fertil Steril 1997;68:83–9. [PubMed: 9207589]
- Rumball A, Adair V. Telling the story: parents' scripts for donor offspring. Hum Reprod 1999;14:1392– 9. [PubMed: 10325301]
- van Berkel D, van der Veen L, Kimmel I, te Velde E. Differences in the attitudes of couples whose children were conceived through artificial insemination by donor in 1980 and in 1996. Fertil Steril 1999;71:226–31. [PubMed: 9988389]
- Golombok S, Brewaeys A, Giavazzi MT, Guerra D, MacCallum F, Rust J. The European study of assisted reproduction families: the transition to adolescence. Hum Reprod 2002;17:830–40. [PubMed: 11870145]
- Murray C, Golombok S. To tell or not to tell: the decision-making process of egg-donation parents. Hum Fertil (Camb) 2003;6:89–95. [PubMed: 12869792]
- Turner AJ, Coyle A. What does it mean to be a donor offspring? The identity experiences of adults conceived by donor insemination and the implications for counselling and therapy. Hum Reprod 2000;15:2041–51. [PubMed: 10967012]
- 12. Daniels KR, Thorn P. Sharing information with donor insemination offspring. A child-conception versus a family-building approach. Hum Reprod 2001;16:1792–6. [PubMed: 11527877]
- McWhinnie A. Gamete donation and anonymity: should offspring from donated gametes continue to be denied knowledge of their origins and antecedents? Hum Reprod 2001;16:807–17. [PubMed: 11331622]
- Golombok S, Lycett E, MacCallum F, Jadva V, Murray C, Rust J, et al. Parenting infants conceived by gamete donation. J Fam Psychol 2004;18:443–52. [PubMed: 15382969]
- Informing offspring of their conception by gamete donation. Fertility and Sterility 2004;81:527–531. [PubMed: 15037397]
- Nachtigall RD, Becker G, Quiroga SS, Tschann JM. The disclosure decision: concerns and issues of parents of children conceived through donor insemination. Am J Obstet Gynecol 1998;178:1165– 70. [PubMed: 9662297]
- Hunter M, Salter-Ling N, Glover L. Donor Insemination: Telling Children About Their Origins. Child and Adolescent Mental Health 2000;5:157–163.
- Hahn SJ, Craft-Rosenberg M. The Disclosure Decisions of Parents Who Conceive Children Using Donor Eggs. J Obstet Gynecol Neonatal Nurs 2002;31:283–293.
- Lycett E, Daniels K, Curson R, Golombok S. School-aged children of donor insemination: a study of parents' disclosure patterns. Hum Reprod 2005;20:810–9. [PubMed: 15677680]
- 20. Kirkman M. Parents' contributions to the narrative identity of offspring of donor-assisted conception. Soc Sci Med 2003;57:2229–42. [PubMed: 14512252]
- 21. Golombok S, Jadva V, Lycett E, Murray C, Maccallum F. Families created by gamete donation: follow-up at age 2. Hum Reprod 2005;20:286–93. [PubMed: 15539442]
- 22. Solomon GE, Johnson SC, Zaitchik D, Carey S. Like father, like son: young children's understanding of how and why offspring resemble their parents. Child Dev 1996;67:151–71. [PubMed: 8605825]
- Klock SC, Maier D. Psychological factors related to donor insemination. Fertil Steril 1991;56:489– 95. [PubMed: 1894027]
- 24. Schover LR, Collins RL, Richards S. Psychological aspects of donor insemination: evaluation and follow-up of recipient couples. Fertil Steril 1992;57:583–90. [PubMed: 1740202]
- Daniels KR, Lewis GM, Gillett W. Telling donor insemination offspring about their conception: the nature of couples' decision-making. Soc Sci Med 1995;40:1213–20. [PubMed: 7610427]
- 26. Birenbaum-Carmeli D, Carmeli YS, Yavetz H. Secrecy among Israeli recipients of donor insemination. Politics Life Sciences 2000;19:69–76.

Mac Dougall et al.

- Kremer J, Frijling BW, Nass JL. Psychosocial aspects of parenthood by artificial insemination donor. Lancet 1984;1:628. [PubMed: 6142329]
- Scheib JE, Riordan M, Rubin S. Choosing identity-release sperm donors: the parents' perspective 13– 18 years later. Hum Reprod 2003;18:1115–27. [PubMed: 12721193]
- 29. Inhorn MC. Interpreting infertility: medical anthropological perspectives. Introduction Soc Sci Med 1994;39:459–61.
- Tober DM. Semen as Gift, Semen as Goods: Reproductive Workers and the Market of Altruism. Body & Society 2001;7:137–160.
- Greenfeld DA, Klock SC. Disclosure decisions among known and anonymous oocyte donation recipients. Fertil Steril 2004;81:1565–71. [PubMed: 15193478]
- 32. Walker, I.; Broderick, P. Politics and Life Sciences. 2003. Donor Gametes and Embryos: Who wants to know what about whom and why?.
- Brewaeys A. Review: parent-child relationships and child development in donor insemination families. Hum Reprod Update 2001;7:38–46. [PubMed: 11212073]
- Golombok S, MacCallum F, Goodman E, Rutter M. Families with children conceived by donor insemination: a follow-up at age twelve. Child Dev 2002;73:952–68. [PubMed: 12038562]
- Vanfraussen K, Ponjaert-Kristoffersen I, Brewaeys A. An attempt to reconstruct children's donor concept: a comparison between children's and lesbian parents' attitudes towards donor anonymity. Hum Reprod 2001;16:2019–25. [PubMed: 11527916]
- 36. Scheib JE, Riordan M, Rubin S. Adolescents with open-identity sperm donors: reports from 12–17 year olds. Hum Reprod 2005;20:239–52. [PubMed: 15539443]
- Lycett E, Daniels K, Curson R, Golombok S. Offspring created as a result of donor insemination: a study of family relationships, child adjustment, and disclosure. Fertil Steril 2004;82:172–9. [PubMed: 15237008]
- Klock SC, Jacob MC, Maier D. A prospective study of donor insemination recipients: secrecy, privacy, and disclosure. Fertil Steril 1994;62:477–84. [PubMed: 8062941]
- Adair VA, Purdie A. Donor insemination programmes with personal donors: issues of secrecy. Hum Reprod 1996;11:2558–63. [PubMed: 8981156]
- 40. Golombok S. Parenting and secrecy issues related to children of assisted reproduction. J Assist Reprod Genet 1997;14:375–8. [PubMed: 9285319]
- 41. Gottlieb C, Lalos O, Lindblad F. Disclosure of donor insemination to the child: the impact of Swedish legislation on couples' attitudes. Hum Reprod 2000;15:2052–6. [PubMed: 10967013]
- 42. Daniels KR, Taylor K. Secrecy and openness in donor insemination. Politics Life Sciences 1993;12:155–70.
- 43. Pettee D, Weckstein LN. A survey of parental attitudes toward oocyte donation. Hum Reprod 1993;8:1963–5. [PubMed: 8288766]
- 44. Heath, J.; Cooke, S. My Story: A Child's Introduction to Donor Insemination. Sheffield; J.W. Northend: 1991.
- 45. Dudley, M.; Neave, G. Issues for families and children where conception was achieved using donor gametes. In: Lorbach, C., editor. Let the Offspring Speak: Discussions on Donor Conception. New South Wales, Australia: The Donor Conception Support Group of Australia, Inc; 1997. p. 125-136.

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#### Table 1

# **Discloser Population Demographics**

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	Egg Donation	Donor Insemination
Total Disclosing Couples	64	48
Women Participating	64 (100%)	47 (98%)
Men Participating	48 (75%)	40 (83%)
Disclosure Stance		
Disclosers	18 (28%)	20 (42%)
Intend to Disclose	46 (72%)	28 (58%)
Age		
Average Age (Range) of Women	45.5 (35–59)	41.9 (28–52)
Average Age (Range) of Men	47.7 (32–64)	48.3 (34–71)
Current Martial Status		
Married	62 (97%)	44 (92%)
Divorced/ Separated	2 (3%)	4 (8%)
Ethnicity <sup><i>a</i></sup>		
Caucasian	119 (93%)	79 (82%)
Hispanic/Latino	1 (1%)	6 (6%)
Other	3 (2%)	4 (4%)
Declined to Identify	5 (4%)	7 (8%)
Median Household Income	\$137,500	\$100,000
Education <sup><i>a</i></sup>		
High School	0 (0%)	8 (8%)
College	52 (40%)	47 (49%)
Post Graduate	70 (55%)	36 (38%)
Declined to Identify	6 (5%)	5 (5%)
Demographics for Donor Conceived Children		
Average Age of First Donor Child – Disclosers	6.0 (2–10)	9.7 (5–19)
Average Age of First Donor Child - Intend to Disclose	2.6 (1–9)	5.3 (1-11)

 $^{a}$  some respondents reported data for spouses who did not participate in the study