

How parents whose children have been conceived with donor gametes make their disclosure decision: contexts, influences, and couple dynamics

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Objective: To describe parents' disclosure decision-making process.

Design: In-depth ethnographic interviews.

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

Patient(s): One hundred forty-one married couples who had conceived a child using donor gametes (62 with donor sperm, 79 with donor oocytes).

Intervention(s): Husbands and wives were interviewed together and separately.

Main Outcome Measure(s): Thematic analysis of interview transcripts.

Result(s): Ninety-five percent of couples came to a united disclosure decision, some "intuitively," but most after discussions influenced by the couples' local sociopolitical environment, professional opinion, counseling, religious and cultural background, family relationships, and individual personal, psychological, and ethical beliefs. Couples who were not initially in agreement ultimately came to a decision after one partner deferred to the wishes or opinions of the other. Deferral could reflect the result of a prior agreement, one partner's recognition of the other's experiential or emotional expertise, or direct persuasion. In disclosing couples, men frequently deferred to their wives, whereas, in nondisclosing couples, women always deferred to their husbands.

Conclusion(s): Although the majority of couples were in initial agreement about disclosure, for many the disclosure decision was a complex, negotiated process reflecting a wide range of influences and contexts. (Fertil Steril® 2008;89:179–87. ©2008 by American Society for Reproductive Medicine.)

Key Words: Donor gametes, donor sperm, donor oocytes, disclosure

Couples who attempt conception with donor sperm or donor eggs face many difficult decisions. These include when to abandon medical treatment using their own gametes, whether to conceive with donor gametes over other options such as adoption, and decisions related to the selection of a donor. Yet the final decision, whether to disclose to their children the circumstances of their conception, is one of the most challenging. Although research has consistently documented high levels of spousal agreement about disclosure (1–4), findings have generally reflected that the partners answered questions indicating a particular disclosure stance at the time the measures were administered. Furthermore, despite extensive research that has focused on identifying parents' ultimate disclosure decisions (4–13), with few exceptions (1, 4), these studies provide only a glimpse of how these decisions were arrived at and little about the dynamics of the couples' dis-

closure decision-making process. Missing is the history of agreement/disagreement and the process by which couples arrived at consensus. Finally, research methodologies that query both the husband and wife have not been widely employed despite suggestions that one needs to talk to both partners to understand fully the decision making that typically occurs in many reproductive and parenting decisions (3, 14, 15).

The aim of this current research was to analyze the decision-making process in couples who conceived using donor sperm (DI) or egg donation using qualitative methodologies that we believe are uniquely suited to the comprehensive examination of involved social and personal issues. By conducting in-depth interviews with both members of the husband-wife dyad, we focused specifically on how couples arrive at a disclosure decision. This included an identification of the contexts and factors that influence their decisions, how couples move from individual perspectives to a shared decision to disclose or not disclose, and how differences of opinion, if they exist, are resolved.

MATERIALS AND 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

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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. A 53-question semistructured and open-ended in-depth interview with the husband and wife together was followed by a 26-question interview with each partner separately approximately 3 months later. If one but not both members of a couple agreed to be interviewed, those individuals were also interviewed. The 1- to 2-hour-long interviews 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.

Because the interview questions were intentionally semistructured and open-ended, we were not attempting to analyze "yes" or "no" responses to specific probes. Rather, broad themes, ideas, and concepts that appeared in the data were identified, and code words defining and referencing these themes were developed. Each paragraph of each interview transcript was 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. For example, this article is based on an analysis of the interview data identified by the codes "tell child" (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), "support" (defined as discussion, description, meaning of instrumental and emotional support, to or from partner, extended family, friends and acquaintances, community groups and organizations, and professionals including therapists, counselors, and physicians), and "policy" (defined as thoughts concerning existing or potential regulation or policy). The coded excerpts were cross-checked by reading the transcripts from which they originated to confirm that excerpts were not misinterpreted by being read out of context. Analysis of couple decision-making dynamics used only interviews in which both partners participated, whereas other themes (i.e., influences on decision making, support received) were culled from the larger set of both individual and joint participant interviews.

Transcripts were numbered and identified as to whether the children were conceived by using DI 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), nondisclosers (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.

Finally, in an effort to deepen our understanding of the nature of couple decision making, we examined the level of agreement over the course of the decision-making process. We defined agreement as both partners expressing similar disclosure desires (i.e., they both wanted to disclose), regardless of the reasons used to support their desire. A difference of opinion was determined when one partner preferred a particular disclosure decision more than their spouse. Although a difference of opinion occasionally indicated absolute disagreement (i.e., one spouse preferred disclosure, the other wanted nondisclosure), it more often meant that one spouse was uncertain or relatively indifferent.

RESULTS

Study Sample

The total study sample comprised 141 couples: 62 couples who conceived with DI and 79 couples who conceived using egg donation. Of the DI couples, 20 (32%) couples had already disclosed, 28 (45%) planned to disclose, 10 (16%) did not plan to disclose, and 4 (6%) were undecided. Of the egg donation couples, 18 (23%) had already disclosed, 46 (58%) planned to disclose, 8 (10%) did not plan to disclose, and 7 (9%) were undecided. Because couples who had already disclosed to their child and couples who intended to disclose to their child were similar in the way they thought about and articulated their disclosure decision, we refer to these two groups jointly as disclosing couples. The demographic data summarized in [Table 1](#) reveal a study population that was predominantly white, highly educated, and affluent. There was no major difference between DI and egg donation couples with respect to sex, ethnicity, occupational status, or number of donor-conceived children. We did find that egg donation families had a slightly higher median household income and educational level than DI families. For egg donation families, the average age of the oldest donor-conceived child was 3.5 years, whereas for DI families the average age of the oldest donor-conceived child was 7.2 years. In general, couple dynamics did not appear to be dependent on whether they had used donor sperm or donor eggs. When findings suggested otherwise, we have noted them.

Couples' Decision-making Dynamics: Initial Agreement

Approximately one half of couples simply stated that no difference of opinion had ever existed between them. Of these couples, approximately a third described coming to their decision "intuitively," saying they "just knew" what their decision would be and had agreed about disclosure from the beginning. These couples frequently commented on their

TABLE 1

Participant demographics.	Egg donation	DI
Total couples, n	79	62
Women participating, n (%)	79 (100)	62 (100)
Men participating, n (%)	55 (70)	49 (79)
Disclosure stance		
Disclosers, n (%)	18 (23)	20 (32)
Intend to disclose, n (%)	46 (58)	28 (45)
Not disclosing, n (%)	8 (10)	10 (16)
Undecided, n (%)	7 (9)	4 (6)
Age		
Average age, y (range), of women	45.8 (35–59)	42.0 (28–52)
Average age, y (range), of men	47.5 (32–64)	48.6 (34–71)
Average age, y (range), of oldest donor child	3.5 (1–10)	7.2 (1–19)
Current marital status		
Married, n (%)	75 (95)	57 (92)
Divorced/separated, n (%)	4 (5)	5 (8)
Ethnicity ^a		
White, n (%)	142 (90)	100 (81)
Hispanic/Latino, n (%)	3 (2)	8 (6)
Other, n (%)	6 (4)	6 (5)
Declined to identify, n (%)	7 (4)	10 (8)
Median annual household income	\$140,000	\$100,000
Education ^a		
High school, n (%)	1 (0.5)	8 (6.5)
College, n (%)	68 (43)	60 (48)
Postgraduate, n (%)	80 (51)	48 (39)
Declined to identify, n (%)	9 (5.5)	8 (6.5)

^a Some respondents reported data for spouses who did not participate in the study.

Shehab. Parents' disclosure decision making. Fertil Steril 2008.

shared values, beliefs, and perspectives on parenting and engaged in dialogue only to confirm the agreement with the other. Although also in initial agreement, the remaining two thirds of these couples affirmed their agreement only after engaging in a process of seeking, evaluating, and discussing information and advice from professionals, available books and other literature, friends, family, and support groups.

Couples' Decision-making Dynamics: Agreement Following Discussion

In the other half of couples, husbands and wives had disclosure attitudes that initially differed. With a single exception, these couples uniformly engaged in discussions about the disclosure decision. The content of such discussions reflected a wide range of contexts and influences that included the couples' local sociopolitical environment, professional opinion, counseling and support network, their religious and cultural background, their extended and immediate family structure and relationships, the child's appearance, and the couple's individual personal beliefs as influenced by sex, early life events

and experiences, adult and/or professional experiences, and ethical values. In the end these discussions culminated in a negotiation between the marital partners that allowed 95% of couples to come to a united disclosure decision.

External Contexts and Influences

Some parents reported that living in a "progressive" area of the country made their decision to disclose less problematic, because they believed their donor gamete children would be well accepted by others. The prevalence and acceptance of the use of assisted reproductive technologies, existing models for alternative family structures (e.g., adopted, single parent, gay/lesbian, multiracial, multicultural), and a politically liberal environment were also cited as contributing to a decreased concern about stigma. A number of parents who decided to disclose to their children reported that they perhaps would have made a different decision if they lived in a part of the country where the sociopolitical climate was more conservative.

Although many DI couples received no counseling at all, most egg donation couples received counseling that was

mandated by the clinic. Others received voluntary counseling at specific decision points or in ongoing personal therapy. Most couples recognized the potential value of counseling, although they often reflected that they had not recognized a need for counseling during treatment but wished for it in retrospect. However, couples did not want to be told what to do or how to think. In general, they expressed a desire for information, options, and guidelines, rather than judgments or personal opinions. Furthermore, because couples recognized the personal and individual nature of third-party reproduction, they wanted counseling to be individualized and strongly objected to pro forma counseling or advice. RESOLVE and support groups were also perceived positively, but of all counseling modalities couples valued peer support most highly, and many would have liked to talk with others about their experience with gamete donation and disclosure.

Among egg donation couples, mental health professionals were the greatest source of professional influence, and physicians most often provided disclosure recommendations to DI couples. In both groups, mental health professionals unanimously encouraged disclosure, whereas physicians were more variable in the advice they gave. Though disclosure was advocated by some physicians, they were the only professionals who encouraged nondisclosure or supported the idea of nondisclosure as an option for the couple.

Regardless of their own disclosure stance, parents consistently expressed the opinion that disclosure decisions are private, are highly personal, and should be left to the discretion of the individual families and not be regulated in any way. Participants stated that their disclosure position was among many decisions they made as parents and that regulating parents' behavior would be a violation of privacy and inappropriately interfere with "intimate relationships." Participants also raised the related question of why they should be singled out for regulations controlling their prerogatives as parents that do not apply to nondonor parents.

Relational Contexts and Influences

Some parents reported feeling apprehensive about their family's response to disclosure because of their family's religious convictions or cultural beliefs. In our sample, both Catholic and Jewish parents expressed concern as did parents of Hispanic and Asian ancestry, particularly with respect to how their children would be perceived and treated by their grandparents.

Participants' relationships with their own parents, adult siblings, in-laws, and extended families influenced the decision-making process. For example, parents who had shared their experiences of using donor gametes with their families and had received emotional support from them reported that it was easier to disclose to their child. On the other hand, parents who had not told family members, in part because of experiencing or anticipating a lack of family emotional support, experienced the disclosure decision as more complex and often associated with considerable anxiety.

The structure of the immediate family, especially with respect to siblings, also figured prominently in parents' decision making. For example, participants who had another donor gamete child cited that this shared experience and the additional emotional support of a sibling made disclosing easier. Conversely, some participants who had another child who was not a result of donor gametes reported feeling concerned about whether disclosing would make the donor gamete child more vulnerable in his/her relationship with the sibling. Regardless of whether their other child was a result of donor gametes, parents sometimes remarked that the competitive nature of their children's relationship with each other left them anxious about how the information might be received or used by their other child.

The child's resemblance to the parents also influenced the disclosure decision. Parents reported that comments about the child's appearance put pressure on them to qualify expressions of physical similarity or dissimilarity by explaining how their children were conceived. As a result, comments about appearance sometimes led parents toward disclosure to clarify the situation and prevent the child from feeling confused. On the other hand, nondisclosing parents were more likely to interpret resemblance in a manner that reinforced their desire to be seen as a genetically related family.

Personal Contexts and Influences

The opinions, histories, and personal beliefs of the individual husbands and wives played a role in the disclosure decision. We found that these beliefs were influenced by early life events and experiences, adult and/or professional experiences, personal philosophies, moral/ethical values, empathy, and the assessment of the possibility of actually maintaining nondisclosure.

Disclosing parents' beliefs about disclosure sometimes resulted from key events in their personal history or early life experience both within their family of origin and in social interactions with friends and peers. For example, some parents described childhood experiences of having been adopted or having family or friends who were adopted, or growing up in a family with family secrets or other unspoken inhibitions about discussing certain "taboo" topics such as sex or divorce. Others commented that they came from very open families where personal matters were discussed routinely and matter-of-factly. However, nondisclosing couples made few references to past personal experiences and ways of viewing the self that influenced their beliefs about disclosure.

Attitudes were also influenced by adult experiences with friends or in the context of participants' professional lives. For example, having observed how other couples successfully disclosed to an adopted child provided some of our participants with a sense of conviction about disclosing. Others were influenced by their professional experience as social workers or psychologists, in which case their disclosure decision was informed by an awareness of the literature on adoption and family secrets.

Beliefs about disclosure were also reflective of general philosophies and personal values about how couples chose to lead their lives and, more specifically, how they aspired to parent their children. For example, some couples saw disclosure not only as an enactment of their sense of values but as a way of modeling such values for the child. Nondisclosing DI couples generally cited a philosophy of parenting in which the importance of biological relationships was minimized, the social paternal role was reinforced, and beliefs about the quality of father-child parenting could be used to assert that “he *is* their father.” Some nondisclosing egg donation couples maintained that through the pregnancy and the exchange of “blood” and other nutrients delivered by mother to fetus, the biological connection was in fact not lost; ergo, the maternal role was preserved and nothing need be told.

Psychological and Ethical Contexts and Influences

We found that parents frequently made direct and indirect reference to ethical and psychological perspectives including those based on rights, principles, the best interests of the child, relational contexts, and empathy. Mirroring the public debate that has surrounded disclosure, parents used these ethical frameworks to support divergent disclosure positions. For example, using rights-based reasoning, disclosing parents claimed that their children had a “right to know how they were conceived,” as well as “the right to know their genetic origins,” and a “right not to be loaded down with some mysterious baggage,” whereas parents who supported nondisclosure expressed their “right to privacy” as a couple or family. Wives who had used donor sperm expressed their concern regarding their husband’s “right to privacy about his medical condition.” Nondisclosing couples spoke of their belief that the disclosure decision was a personal choice and invoked “their right to choose” nondisclosure as part of a more general right to determine how they raise their child.

Parents also used principled reasoning, primarily with their decisions to disclose. Disclosing parents most often cited the principle of honesty but also thought that telling was their responsibility as parents and that being open with information was best for society in general. The only example of principled reasoning used for not disclosing was voiced by a wife who had conceived with donor sperm and was committed to honoring her husband’s deathbed request.

Both disclosing and nondisclosing parents used welfare of the child reasoning and expressed their concern about the consequences of their disclosure decisions for their children’s psychological and developmental well-being. Parents who chose to disclose expressed the belief that not telling their child would undermine their child’s sense of self, cultivate a sense of shame, and leave their child vulnerable to the accidental disclosure from someone other than the parents. They also cited that the child may need to know of his or her origins for medical or health reasons and wanted to relieve the child of worries about having the health problems of the nongenetic parent. Nondisclosing parents also made

arguments based on what they believed was in their child’s psychological and developmental best interests and emphasized the potentially damaging consequences of telling their child. They believed that not telling protected the child from an unnecessary emotional burden and avoided potential hurt and confusion, difficult identity issues, other people’s negative reactions, and feeling isolated in a world where there is still social stigma about having been conceived via donor gametes.

Although parents used ethical reasoning to support their disclosure decisions, they often did so in the context of how their disclosure decision would affect the interpersonal relationships in their children’s lives. Although these parents’ primary concern was often with the parent-child relationship, they were also cognizant of the effects their disclosure decision could have on the child’s current and future relationships with siblings, grandparents, extended family, and friends. Many disclosing parents invoked empathy with the child as part of their decision-making process and voiced the belief that not disclosing to their children would be a violation of a relationship built on honesty, trust, and respect. Nondisclosing parents emphasized their desire to protect the child’s relationship with the nonbiological parent and prevent potential hurt and harm in their relationships with their donor gamete children.

Finally, parents considered a pragmatic assessment of the likelihood that the information could be kept hidden. Disclosing parents frequently concluded that, from a practical perspective, nondisclosure was not a secret that could be kept. Cited reasons included their belief that the child looked nothing like parents, that so many people had been told that it would probably “slip,” and that the child would eventually find out through future genetic technology or after an experiment in high school biology class. On the other hand, nondisclosing parents believed that it was a secret that could be kept and that the information would be easier to control if the child did not know. Although they expressed the conviction that “there is no reason to tell” or “there is no need to disclose,” these parents also stated that they would change their disclosure stance if disclosure was needed to protect the physical health of the child, although such scenarios were thought to be unlikely.

Couples’ Decision-making Dynamics: Negotiation

For spouses whose disclosure attitudes were initially disparate from each other, the quality of their disclosure discussions was notably more varied and complex than the interactions between couples who had initially agreed. Almost all couples who were not initially in agreement came to a united decision through a negotiation process in which ultimately one partner deferred to the wishes or opinions of the other. Although we found no clear relationship between which partner maintained their genetic connection and which partner deferred, we did observe that, in disclosing couples, women were more in favor of disclosure and men frequently deferred to their wives, whereas, in nondisclosing couples,

men always preferred nondisclosure and women always deferred to their husbands.

The couples' ultimate decision was reached through interactive patterns that illustrated a variety of approaches to conflict resolution. At the most basic level, one partner might simply remove himself or herself from the decision-making process. This passive deferral usually reflected an absence of feeling for or against disclosure and thus served to bring a rapid, low-intensity resolution to the decision making. However, in most couples, the final deferral was the result of either a prior agreement or arrangement, attribution of some experiential or emotional expertise, recognition of greater emotional impact, or direct persuasion by the spouse.

The most direct example of a prior arrangement was when one partner had agreed to use donor gametes only if the other had agreed to a particular disclosure decision. This acquiescence could have been identified explicitly, or there might have existed an unstated, implicit understanding of the arrangement. In another example, one partner deferred to the other because of the perception that he or she had benefited previously from some prior support of the spouse, and, therefore, in the current context of making a disclosure decision, it was perceived to be the spouse's turn to benefit. In some relationships, the benefit exchange was related to who had had more input in the decision to use a donor.

Deferral after the attribution of some experiential or emotional expertise was observed when one partner was designated as more "fit" to make the decision because of their perceived accumulation of relevant knowledge or experience. Men most often deferred to their wives because they believed either [1] that women were more qualified and had greater aptitude for tasks that fell into the emotional domain, especially those involving their children, or [2] that the wife had done more research on the issue or had relevant personal or professional experience and thereby possessed greater cognitive knowledge or competence concerning disclosure.

One partner might defer to the other because of a perception that disclosure would have a greater emotional impact on one spouse. Often thought to be at stake in both disclosing and nondisclosing parents was the relationship between the nonbiological parent and the child. Under these circumstances, consideration of the other's feelings was paramount, and themes of concern, respect, and protection of the spouse emerged in these couples' discourse.

Finally, deferral could also be a response to persuasive strategies used by the spouse. Persuasion was frequently characterized by verbal communications that indicated that one partner felt much more strongly than the other about the decision. The basis for this conviction could be primarily emotional or rational. For example, a partner might cite relevant and compelling personal history that harkened back to painful childhood experiences or memories of family secrets that these parents did not want repeated. Rational arguments frequently were based in the likelihood that the child would eventually learn the truth through either future DNA testing

or inadvertent disclosure. At its most extreme, one partner could attempt to influence the other through the use of strong language, persistence, interrupting, or unilaterally claiming special expertise in the decision-making process.

Couples' Decision-making Dynamics: No Decision

The decision-making dynamics of undecided couples were marked by ambivalence and statements reflecting conflict, confusion, and dissatisfaction with either disclosure stance. Despite still being in the process of decision making, some couples were more actively engaged than others, and, as a reflection of their ambivalence, almost all undecided couples were consciously putting off the decision to a later time. Yet regardless of their uncertainty about disclosure, these couples unanimously had engaged in discussions with each other on the topic. A few parents described an intense internal debate that resulted from conflicts between values of honesty and openness and a desire to protect relationships with the child or partner. Several of the undecided parents articulated that making such a decision felt like a huge responsibility. One mother described her belief that this decision was really a decision for her daughter and stated that decisions made on another's behalf are difficult. Conflicting advice from family, friends, and medical and mental health professionals also contributed to and exacerbated feelings of ambivalence.

Some undecided couples experienced distress about whether they would make the "right" decision. One father described the experience of decision making as "terrifying and challenging." Although ambivalent sentiments were also expressed by some disclosing and nondisclosing parents, the language and comments of undecided couples suggested a greater poignancy and eloquently conveyed just how angst-ridden they felt. Although the concerns of undecided couples were similar to those voiced by nondisclosing parents, the existence of an opposing point of view (whether internal or originating from their spouse or an outside influence) left these parents unsettled, immobilized, and unable to make a decision. Illustrating this paralysis, their conversations reflected avoidance and denial with expressions such as "we just don't think about it," "we don't mention it," and "we've decided to deal with it by not dealing with it."

DISCUSSION

On the basis of interviews with 254 parents of children conceived with donor gametes, we found that 95% of study couples came to a united disclosure decision either through initial agreement or by negotiation after discussions that reflected a wide range of contexts and influences. Because previous research with DI couples has reported high levels of disclosure agreement (1–4, 13) we suggest that this consistent finding may result from several factors. First is the likelihood that the process of choosing gamete donation may self-select for couple coherence. On the basis of estimates of the number of infertile couples in the United States (approximately 1 million) (16), the prevalence of male factor infertility

(approximately 20%–40%) (17), and the number of DI offspring conceived on an annual basis (30,000) (18), it appears that only a minority of couples with male factor infertility have chosen this method of conception. By confronting the emotional issues of their infertility, making decisions about abandoning medical treatment using their own gametes, deciding whether to conceive with donor gametes over other options such as adoption, and making decisions related to the selection of a donor, these couples have already demonstrated their decision-making proficiency. That these attributes are not limited to DI couples is suggested by the finding that egg donation couples score higher than norms in cohesion and lower than norms on conflict on the Family Environmental Scale (4). Because we rarely found couples in which one spouse absolutely preferred disclosure and the other nondisclosure, it also seems likely that couples consciously or unconsciously begin to address disclosure as part of their decision to proceed with gamete donation itself.

In further support of this conjecture we found that approximately half of disclosing and nondisclosing couples stated that no difference of opinion had ever existed between them with many stating that they “just knew” what their decision would be and had agreed about disclosure from the beginning. Not only had these couples overcome the obstacles presented by infertility-related decision making, but they frequently had similar life histories and shared values, beliefs, and perspectives on parenting. These observations are in alignment with research suggesting that intuitive, nonverbal modes of decision making often lead to a mutually satisfying decision because they evolve out of what the couples “know about each other” and reflect standards learned from reference groups, cultural norms, relational precedents, or shared beliefs, backgrounds, and experiences (19). Although appearing to be completely unconscious, these implicit agreements may reflect the couple’s belief in relational dynamics that occur “more naturally,” especially in couples motivated by the desire to please the spouse and to have marital harmony (20).

However, two thirds of the couples in initial agreement did not reach their consensus intuitively and noted that more deliberate, explicit conversations were an important aspect of the decision-making process. The need to engage in a discourse reflected, in part, the seriousness with which the couples regarded the question at hand. For these couples, a good decision was one that resulted from scrutiny and a fuller understanding of the rationales for disclosing. This is consistent with research suggesting that explicit processes tend to be more common for major life decisions (21). An explicit process may reflect the particular communication orientation of the couple as well, in which open communication is highly valued and imbues most interactions. For a number of participants, our study interviews became a conduit for reinitiating and expanding the conversation about disclosure.

When couples were not in initial agreement, in almost all cases, ultimately one partner deferred to the wishes or opinions of the other. This deferral could occur because there was a *quid pro quo* arrangement about the decision, one partner

was ascribed with greater emotional or experiential expertise on the subject, one partner was believed to bear a greater emotional impact from disclosure, or one partner was persuaded by the other. Persuasion could include the use of some compelling personal history of a partner or rational arguments about the likelihood of eventual, unplanned disclosure. Less commonly, some participants persuaded their partners through strong language, persistence, interruption, claiming expert knowledge, or even (rarely) unilateral decision making.

In interviews with 48 DI couples in New Zealand, Daniels et al. also noted different patterns of couple agreement (1). These included partners of a like mind, partner deferral (e.g., partner cooperation despite differing views, wives acquiescing to protect their husbands), and decisions reflecting one partner’s views (1). This analysis is consistent with our descriptions of “intuitive” initial agreement, deferral, and the use of persuasion strategies, respectively. Daniels et al. also identified specific conversational dynamics, culled from observable interactive elements in the couples’ discourse, including elements found in our description of persuasion strategies, such as partners talking past each other or one partner dominating the conversation.

Although we found no clear relationship between which partner maintained his or her genetic connection and which partner deferred, we did observe that, in disclosing couples, men frequently deferred to their wives, whereas, in nondisclosing couples, women always deferred to their husbands. Men often deferred to their wives because either they believed that women were more qualified and had greater aptitude for tasks that fell into the emotional domain, especially those involving their children, or they believed that the spouse had done more research on the issue or had relevant personal or professional experience and thereby possessed greater cognitive knowledge or competence concerning disclosure. On the other hand, the description by Daniels et al. of spousal deferral points to protective, facilitative, and compromising tendencies on the part of the female partners to protect their husbands from possible stigma (1). Because we found only women deferring to their husbands in our nondisclosing couples (whether DI or egg donation), such factors may have existed here as well.

Although one could imagine a partner feeling overpowered or helpless as a participant in the process, we found that the deferring partner almost always appeared satisfied with his or her position in the decision making. *Quid pro quo*-type agreements appeared to allow both spouses to have their respective needs met, and partners who deferred to their partners’ strong personal beliefs (often influenced by intensely emotional personal experiences) seemed to respond with sympathy and a readiness to accommodate their partner’s feelings. Indeed, it was in this deferral dynamic that feelings of marital caring emerged most clearly.

Despite the relatively large number of participants, an acknowledged limitation of this work is the self-selected

sampling that results from restrictions that appropriately protect confidential medical information by permitting communication with couples only after they have expressly given their permission to be contacted. This selection bias provides a likely explanation for our observation that only 20% of participating couples were nondisclosing or undecided. Lycett et al. have suggested that research participation may be interpreted as a threat to maintaining secrecy (21), and our previous research indicated that DI couples who were willing to be interviewed were more likely to have disclosed than those unwilling to be interviewed (2). Furthermore, the observations that there may be a trend of increased approval of DI as a function of educational and occupational status (22) and that less-educated parents are more likely to choose an anonymous donor compared with more-educated parents (23) suggest the possibility that respondents from our predominantly white, highly educated, and affluent demographic may be inherently more open to disclosure and thus may explain the similarity in the proportions of egg donation and DI participants who preferred disclosure and nondisclosure, respectively. In addition, because our sample was drawn from a geographic region widely known to be one of the most socially and politically liberal in the United States, we have some cause to consider that the values and attitudes expressed may reflect this sociopolitical view.

Cognizant of limitations of interpretation that may result from self-selection bias and the cultural variables unique to a specific local community, we believe that the usefulness of this analysis resides in the description of the disclosure decision-making process as one influenced by multiple factors including the sociopolitical environment of the community, the couples' friendships and support network, counseling and professional opinion, religious and cultural background, extended and immediate family structure and relationships, the child's appearance, and the couple's individual personal beliefs. These personal beliefs, in turn, reflected the influence of early life events and experiences, adult and/or professional experiences, and ethical/moral values. Furthermore, these contextual layers and influences were not necessarily independent or mutually exclusive but could be interwoven and overlapping. In their interview study of 31 Midwestern U.S. couples using egg donation, Hahn and Craft-Rosenberg identified similar influences including multiple ethical/moral frameworks, relational issues and concerns, resemblance, concerns over inadvertent disclosure, and the contexts of community (including stigma, prejudice, and acceptance of advanced reproductive technologies), religion, family, and the parents' personal experiences (4). We also noted the use of empathy by disclosing couples, as did these authors, and conjecture that disclosing parents' empathy with their children was in many cases a powerful psychological tool that led them to a conclusion that was both emotionally congruent with and reinforcing of their basic disclosure attitudes.

That thoughts, feelings, and beliefs about disclosure derive from a myriad of cultural, familial, and personal influences is

not surprising, but the profound salience and variety of these myriad contexts clearly underscores the highly personal and emotionally charged nature of the disclosure decision. Although much has been written on the ethical issues of disclosure or nondisclosure, identifying and exploring the origins of husbands' and wives' belief systems may yield more useful insights than if the disclosure decision is viewed as a calculation of relative ethical values by disembodied and autonomous moral agents. Indeed, one of the basic ethical quandaries of the disclosure decision is why nondisclosure has long held considerable practical and emotional appeal for the parents of donor gamete children despite the recognition that truth telling is a universally recognized ethical principle.

Regardless of their own disclosure stance and the strength of their own convictions, couples were reluctant to judge other parents' decisions. Recognizing that the personal circumstances of people's lives and families are unique and that "good parents may arrive at different conclusions," they consistently voiced opposition to regulation and expressed the opinion that disclosure decisions are private, are highly personal, and should be left to the discretion of the individual families. Despite ambiguity and uncertainty, parents compassionately accept that there may be a variety of ethical responses and as such support a moral pluralism that nurtures tolerance and allows for the possibility that parents may handle the ethics of disclosure differently.

We found that couples are given and seek the opinions and perspectives of people outside the marital dyad, including family, friends, other DI/egg donation couples, and medical and mental health professionals. The historical disparity between disclosure advice given by mental health professionals and physicians to DI couples (24) was reflected in our data with physicians being the only professionals to support nondisclosure and mental health professionals uniformly urging disclosure. In the United States, egg donation patients typically are required to attend a one-time meeting with a mental health professional. The content of such meetings varies, though discussions of the disclosure issue are generally recommended (25). On the other hand, couples electing DI typically are not required to consult with counselors, and the physician is often left to assume the responsibility for dispensing professional advice.

We found that the parents interviewed in this study echoed the conclusion of Brewaeys et al. that counseling should be individualized "rather than provide a priori advice" (6), particularly because research suggests that disclosure decisions are not strongly influenced by counseling (4, 8, 12) and that parents "for the most part follow their own convictions on this matter and ignore clinicians' recommendations if they disagree" (12). Although individual counseling appeared to be helpful and appreciated by study participants, particularly when delivered without judgment or directive personal opinion, peer support, often in the form of professionally led groups, was most highly valued. It seems likely that peer support not only reduces feelings of isolation and stigma by

normalizing the donor experience but provides for information acquisition derived from the shared, personal, lived experiences of other parents in the same unique life situation.

Nonetheless, we believe that this analysis may provide useful insights and perspectives to physicians and mental health professionals as they help couples identify, assess, and explore the variety of relational patterns, persuasion strategies, and deferral dynamics that are part of the decision-making process. By recognizing and acknowledging the intensely personal nature of the disclosure decision, professionals can assist the patient or couple to make a decision that is most consistent with their culture, life experiences, values, and relationships.

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