

Title

Oocyte Donation Disclosure Decisions: A Longitudinal Follow-Up at Middle Childhood

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Abstract

Few studies have captured oocyte donation (OD) parents' decision processes about intended and actual disclosure over time. Likewise, OD children's perceptions about their family composition during middle childhood is underexplored. To address these gaps, a longitudinally followed cohort of OD recipient families was invited to participate in a qualitative, follow-up study. With an 86% response rate after 12 years, families were comprised of oocyte recipient mothers ($n = 6$) and biological fathers ($n = 6$) representing 12 donor-oocyte conceived children ($M = 10.33$ years). Of the 12 children, two that were aware and two that were unaware of their conceptual origins completed conversational interviews. Only one family in the initial cohort disclosed OD to their children by the 12-year follow-up, despite 43% of parents intending to disclose and another 43% undecided about disclosure during pregnancy. Four parental disclosure patterns emerged at 12 years: *Wanting to Disclose*, *Conflicted about Disclosure*, *Not Planning to Disclose*, and *Having Disclosed*. Children that were unaware of their conceptual origins displayed no knowledge of their method of conception. There is a need for family-centric interventions to assist *Wanting to Disclose* parents in their disclosure process and *Conflicted about Disclosure* parents in their decision-making process post-OD treatment.

Keywords

assisted reproductive technology, donor conception, egg donation, family research, qualitative research

Oocyte Donation Disclosure Decisions:

A Longitudinal Follow-up at Middle Childhood

The use of oocyte donation (OD) to establish embryos continues to rise worldwide (Ishihara et al., 2015). Estimates indicate the United States (US) leads the world with an overwhelming share (55.8%) of the total number of OD babies born followed by Spain (16%) and the United Kingdom (2.9%) (Ishihara et al., 2015). Parents in the US can choose whether, and if so, when and how to inform their children about the child's conceptual origins. For the past several decades, there has been a strong global trend toward advocating disclosure about conceptual origins to children conceived using gamete donations (oocyte, sperm, embryo) and/or surrogacy (Daniels, 2007; Greenfeld, 2008; McGee, Brakman, & Gurmankin, 2001; Sabatello, 2015). Although practice guidelines in the US have advocated for disclosure since 2004 (Ethics Committee of the American Society for Reproductive Medicine, 2004, 2018), there remains a lack of consensus regarding counseling families about disclosure and, in particular, whether directive counseling (favoring openness) for OD and other gamete donation parents is ethically or morally justified (de Melo-Martín, 2014, 2016; Raes, Ravelingien, & Pennings, 2016). In fact, a 2017 editorial advocating a neutral position to parents about disclosure to donor conceived children (Pennings, 2017) garnered immediate worldwide responses that refuted the notion of secrecy (Crawshaw et al., 2017; Golombok, 2017; Pasch, Benward, Scheib, & Woodward, 2017). Nonetheless, several countries (e.g., Finland, Sweden, United Kingdom) have passed legislation to encourage disclosure and transparency in gamete donations (International Federation of Fertility Societies, 2013) and leaders in genetic testing and direct-to-consumer technologies have questioned whether the end of not disclosing the conceptual origins is near (Harper, Kennett, & Reisel, 2016; Phillips, 2016).

Despite a growing sociopolitical trend toward disclosure and continued evidence that OD family functioning is high when disclosure occurs (Blake, Jadv, & Golombok, 2014; Golombok et al., 2002; Lycett, Daniels, Curson, & Golombok, 2004), we and others in the US have found that 18% to 50% of parents do not plan to disclose or are uncertain about whether to disclose the OD origins to their children (Applegarth, Kaufman, Josephs-Sohan, Christos, & Rosenwaks, 2016; Hershberger, Klock, & Barnes, 2007; Klock & Greenfeld, 2004; Shehab et al., 2008). In countries where disclosure to the child is encouraged via governmental legislation, the reluctance by OD parents is lower, approximately 8% to 39% for OD families, with younger parents reporting more openness than their older counterparts (Isaksson, Sydsjö, Skoog Svanberg, & Lampic, 2012; Söderström-Anttila, Sälevaara, & Suikkari, 2010). Although disclosure of conceptual origins to the resulting children is primarily founded on studies of sperm donation, difference in disclosure decisions among the various types of gamete donation is emerging. In a study from the United Kingdom, Readings and colleagues (2011) found that OD parents disclosed the conceptual origins to their children more readily than donor sperm parents but less often than surrogacy parents (Readings et al., 2011). Family structure may also provide a foundation for disclosure as lesbian parent families informed their children about the use of donor sperm earlier than heterosexual parents and heterosexual solo parents tended to inform their children earlier than heterosexual couple parents (Beeson, Jennings, & Kramer, 2011).

Much of what is known about gamete donation parents' disclosure decisions in the US has been derived from studies that evaluate disclosure at one time point. In one of the few US studies examining decision processes over time, Applegarth et al. (2016) invited OD parents of a child or children delivered between 1992 and 2003 to participate in a seminar on issues about OD and disclosure and/or complete research questionnaires to ascertain demographic data,

retrospective and current information about disclosure, and parental advice about disclosure. The investigators found that of the 46 families that participated (72 parents with children aged 7 to 19 years) only 43% of the parents had disclosed to their offspring as intended, 39% still intended to disclose, 9% were uncertain, and 9% did not plan to disclose. The average age of the children at the time of disclosure was 5.5 years (range = 1 – 15 years). A recent systematic review identified “a myriad” of interwoven factors that influence gamete donation parents’ disclosure decisions (Indekeu et al., 2013); however, Applegarth et al. (2016) concluded the predominant reason for disclosure among the parents who reported telling their children were the child’s right to know, the desire to be open and honest, and the perception that family secrets are harmful. Among the 39% of parents who still intended to disclose, the predominant reasons for delayed disclosure included “never finding the right time” and uncertainty about how and when to disclose (Applegarth et al., 2016). Reasons for not disclosing included concerns about the child’s emotional well-being and/or no reason to tell (Applegarth et al., 2016).

Of particular interest is that across all disclosure studies children’s voices about how they know and conceptualize their family are virtually non-existent. Yet, sperm donation parents, who had not disclosed by the time their children were age 16, reported that many of their children spontaneously raised questions about their origins, family, and connectedness by posing questions about dominant and recessive genes (e.g., eye color, tongue roll) indicating to those parents there might be some suspicion or awareness of secrecy within the family (Daniels, Grace, & Gillett, 2011). Whereas lessons in school on genetics and biology were the major impetus for questions raised by the children (Daniels et al., 2011), other investigators have made similar observations about unintentional disclosure through information learned at a genetics class at school, via blood tests, or DNA testing (Beeson et al., 2011; Jadv, Freeman, Kramer, &

Golombok, 2009). Despite these findings, we were unable to locate studies that evaluated donor conceived children's knowledge about their genetic origins and/or definition of family, especially among children who are supposedly unaware of their donor origins. The few studies involving children have instead focused on children's disclosure experiences after they were aware of their donor conception; in 7 to 10 year-olds (Blake, Casey, Jadv, & Golombok, 2014), in adolescents (Scheib, Riordan, & Rubin, 2005), and in families headed by solo mothers (Zadeh, Freeman, & Golombok, 2017; Zadeh, Jones, Basi, & Golombok, 2017).

With this background information, the purpose of this follow-up study was to examine how disclosure decisions were unfolding in the cohort of eight families who participated in our OD research 12 years prior and explore children's understanding about family composition at middle childhood. Thus, the specific research questions were: (1) have the parents followed through with their initial intentions as expressed by the pregnant, OD recipient partners about disclosing the conceptual origins to their child(ren) 12 years ago?; (2) what are the decision patterns of OD parents regarding disclosure?; and (3) using our novel methods, how do middle-childhood aged children who have/have not been told by their parents about their conceptual origins describe their family?

Material and Methods

This was a prospective, longitudinal study with data obtained and analyzed using a qualitative approach. The study was approved by the University of Illinois at Chicago Institutional Review Board.

Participants and Setting

Families in this 12-year follow-up study are a subsample of a larger study examining OD kinships (reported elsewhere). The initial sample of eight families, comprised of eight pregnant,

heterosexual OD recipient women, was recruited at a large, urban fertility center. Each pregnant woman took part in two in-depth phone or face-to-face interviews (16 interviews) between May and December 2004 when they were between 9 and 23 gestational weeks. In the initial study we examined disclosure decisions (Hershberger et al., 2007), overall experiences with OD (Hershberger, 2007), and perceptions of clinical care (Hershberger & Kavanaugh, 2008). Of the eight participants, seven had given permission to be re-contacted about follow-up studies. There was no contact with the participants from the time of the initial study in 2004 until we re-contacted each of the seven women in 2016 to inquire about their interest in participating in an expanded, follow-up study. Although we were able to establish contact with all seven women, one indicated she was not planning to disclose the OD conception to her children and chose not to participate in the follow-up study. The remaining six women agreed to participate and all served as the gateway for providing information about the study to their partners and children. The six women and their partners (all biological fathers) comprise the parents in the sample for the current follow-up study. Collectively, they represented 12 OD children ($M = 10.33$ years, range = 8 to 11 years). Four children from two families whose parents had given parental permission for participating in the study, were invited to participate using an art-based, Draw-and-Tell Conversation interview. At the 12-year follow-up, data were collected from the parents ($n = 12$) and children ($n = 4$) from May to July, 2016 at the parents' homes or other quiet, private location and represent the 6 families in this study at the 12-year follow-up.

Measures and Analysis

The parents completed digitally recorded face-to-face ($n = 6$) or phone ($n = 6$) interviews carried-out by the first author (PEH) who also kept field notes for each of the interviews. Parents were given the option of completing the interviews separately (solo) from their partner or jointly

with their partner. Because our aims were not to validate individual partners' statements and also because male voices are lacking in infertility research, parents were provided with options for interview type to optimize participation. Only two of the families choose joint parental interviews. The interviews ranged from 20 minutes (a separate male interview) to 75 minutes (a joint parent interview) with a mean of 45 minutes.

After completing a short demographic questionnaire, the parent's interviews began with a broad question, "Please tell me what it has been like for you to be a donor-egg recipient mom [or father] of a/an egg-donor child(ren) these past 12 years." Use of a broad open-ended question was a successful technique for obtaining rich data in our initial disclosure research (Hershberger et al., 2007). Thus, the interview guide for the follow-up study built upon the successful questions and strategies used in the initial interview guide including our review of the literature (Hershberger, 2004) and our clinical practice expertise. As each interview progressed, parents were asked specific follow-up questions and probes about their disclosure decisions such as, "How has your decision about telling your child(ren) changed over time, if at all?" Table 1 provides examples of the questions and probes contained in the interview guide.

The analysis followed tenets of qualitative content analysis (Hsieh & Shannon, 2005). To capture and integrate the multiple data sources within the family-centric research, the parental interviews were first transcribed verbatim, verified for accuracy and entered into ATLAS.ti, a qualitative software that assists with data management and analysis. Then, incident coding took place whereby each incident (e.g., an action, belief, event, or perspective) pertaining to disclosure within each of the parental interviews was identified. Each individual partner's responses were coded independently, even in the joint interviews. Incident codes were then compared between each of the coupled partners and summarized for similarities and differences

within each family to maintain the family-centric focus. Last, the codes were compared across families that led to collapsing of the codes into categories and patterns (Ayres, Kavanaugh, & Knafl, 2003; Patton, 2015). Data obtained from the pregnant, OD recipient women's interviews in the initial study were also reviewed, entered into an analytic journal, and served to substantiate the women's recall of their initial disclosure decisions as well as clarify and expand contextual information.

Following assent, each of the children completed a Draw-and-Tell Conversation, which is a novel, art-based, child-centered approach to interviewing children. The Draw-and-Tell Conversation is a technique that was developed by the second author (MD) and has been used successfully with school age children in exploring children's perceptions about genes, genetic risk, family genetic relationships, and inheritance (Driessnack, 2009; Driessnack & Gallo, 2013). The Draw-and-Tell Conversation interview begins with a study-specific art directive. In this study, children were instructed to "Draw your whole family." Then, the children were interviewed about their drawing using age-appropriate questions and probes (e.g., "Tell me who is/is not in the drawing," "Please talk about each person in the drawing and their role in the family," "Talk about anyone else who has helped/helps to make this a family," "Tell me how it is that things get passed on/down in families"). Field notes were compiled during the children's interviews. As a final step, peer debriefing meetings with the interdisciplinary team took place during data collection with the first (PEH) and second (MD) authors and as the analysis ensued with all authors to collectively analyze and integrate the data from all sources.

Results

Family Characteristics at the 12-Year Follow-Up

Of the six families, five had used anonymous OD and one family used a known donor. The majority of parents remained married to the same partner as when the initial study took place however, one family reported recent marital separation. Parents denied participating in professional counseling about OD or disclosure post-treatment; all had received pre-treatment counseling 12 years previously at the recruiting center. The family members were all Caucasian, residing in a Midwestern urban area in the US, and the predominant religion was Roman Catholic. The 12 parents were well-educated and represented a wide-range of professionals (e.g., attorney, nurse, police officer). The mean age of the parents was 52.5 years (range 45 – 58 years) for mothers and 52 years (range 45 – 62 years) for fathers. The four children were between 8 and 11 years ($M = 10.25$); two children (females) had been told of their OD origins and two children (males) had not been told.

Initial Disclosure Decisions During Pregnancy and at the 12-year Follow-Up

Among the six families, only one family had informed their children about their OD origins at the time of the 12-year follow-up study compared to the initial disclosure decisions made during the OD pregnancy where three families were planning to disclose and two families were undecided about whether to disclose. The one remaining family intended not to disclose during the OD pregnancy as per a contractual agreement with the known donor and adhered to their initial decision over the 12-year span.

Parental Disclosure Patterns

In the following paragraphs, insight into parents' decision processes over time is described through the typology of four parental disclosure patterns (*Wanting to Disclose*, *Conflicted about Disclosure*, *Not Planning to Disclose*, and *Having Disclosed*) that emerged from the data. Direct quotes are used to enhance understanding and italics have been added to

words or phrases where the participant placed emphasis when speaking. Pseudonyms for parent's and children's names and participant codes ("M" = Mother" and "F" = Father) along with the Family's coded number (i.e., 1 – 7) are used to promote clarity and meaning while preserving confidentiality.

Wanting to Disclose

In this cohort, two families (Family 1 & Family 7) representing five OD children, reported an initial intention to disclose during the OD pregnancy but had not done so at the 12-year follow-up. In these *Wanting to Disclose* families, the parents' decisions about disclosure did not change over time, rather, the parents perceived barriers that were preventing them from disclosing such as interpersonal conflict with wanting to tell their children and frustration with themselves, at times, for not yet disclosing the OD conception to their children. The parents voiced multiple reasons for not telling, including not fully thinking through disclosure during the OD treatment process and the demands of life itself when caring for a young family.

The IVF process is overwhelming – emotionally, physically, cognitively – and this does not leave time to really think things through. [F1]

From years 0 to 7, 8, 9 10 you're just trying to manage your kids, where they need to be ... unless some medical issue has emerged. You're just trying to parent at your best. [F7]

Adding to the challenge of parental disclosure was the outward appearances of the family members in that the children resembled the parents. For example, M7 said,

Our daughter, Megan and [son] Mitch – Mitch, he looks exactly like Bob [husband/biological father] when he was a little guy and Megan has a lot of my characteristics so everybody was like, 'Oh my God, Mitch is Bob and she is you, she looks just like you, she is *just like you*. [M7]

Obviously they [children] look so much like us that there isn't any questions to as it's like you know that like I guess could be a flag to them that it wouldn't be their parents. [F1]

The families also discussed deeply personal issues as well as social issues that underplayed their ability to disclose to their children. A predominate personal issue was grappling with the grief and loss of infertility even after 11 years of parenthood. M1 shared,

I'm afraid that maybe they won't understand, that *I wasn't able to have them you know naturally* (voice cracking and eyes tearing). In the same breath I want them to understand that I couldn't love them anymore then you know, to me, they are my only sons. I carried them and everything like that. [M1]

Larger social issues, stigma, and experiences also served to keep the parents silent. M7 explained:

I mean we had our kids in a Catholic school and it just so happened that, oh gosh [an IVF center opened] like two blocks away from our church and their school -- and our church was just up in arms about it and picketed and tried to do all this and that. We heard that ... for junior high the religion teacher was basically talking about how IVF was *a sin*... So that is a concern of mine but I feel like we can overcome that but it is something that I do think about that cause it's an issue. It's an issue in our particular parish... You know I think that for kids who are adopted, you know, even though it's a pretty similar situation as far as birth mothers and your biological parents, it's a whole different challenge and I just, you know, I just feel like there will be a stigma for them [her children]. They will feel, yeah, different and not in a good way you know what I mean. [M7]

A huge barrier to disclosing for these families was not knowing *how* to tell their children, concerns about how their children would react, and whether the knowledge about their conception would change the dynamics of the parental relationship – especially the maternal relationship.

There's no question in my mind that we won't tell them -- we will tell them someday I just don't know when or how, but we will. [M7]

A lot of times when we do things [genetic projects] for school, it really gets me because I really know that they don't share those genes with me. Sometimes I'm afraid that if we do tell them, they will get upset and they won't understand. That's the hardest part about the process, is if you are going to tell the kids... And again you know it's hard because I selfishly sometimes don't want to say anything, but I realize how important it is and hope that they will understand. [M1]

F7 described his difficulty in finding a “safe way” to tell his children. He went on to articulate these parents' sentiments when he discussed future research that he would recommend, he said,

Trying to figure out [disclosure] and see what other people have done and how they did it and what the kids reactions were to that, you know. Then, when the kids heard they'd take that information or what do they do then after. [F7]

Another challenge holding back disclosure for parents was knowing how to tell children when there were OD children of multiple ages in the family. M1 voiced,

It's hard because I want to tell Eric [eldest son], but Eric and Mason [youngest son] are so close. Even now, they share a lot of things so it's even harder...So I think that's what makes it harder [to disclose] -- with the younger sibling. [M1]

Conflicted about Disclosure

For the two families (Family 3 & Family 4) that were initially undecided about disclosure during the OD pregnancy, they remained conflicted about whether to tell their respective three children at the 12-year follow-up about OD. In Family 3, the father did not want to disclose and the mother expressed indecision about whether to disclose.

We don't have the least thought of it [OD] being appropriate to share with him or the least need. *Period.* [F3]

I'm more undecided. He's [father] definitely not. He doesn't want to tell. [M3]

Family 4 expressed an openness with disclosure that was not readily apparent in the initial interviews, however, the parents remained uncertain about disclosure.

We are at the point where we, at first, it was there was no way where we were ever going to tell our children - it's not necessary - but with time sometimes your perspectives and your viewpoints change and the past conversations seem maybe one day we should disclose and yeah maybe we should - but we should - but we haven't really got to the point where we are serious about, about making that decision. I don't know if we will -- not saying yes or no right now -- but I think we're not prepared right now; I don't know if we will be. If or when. It's a tough one. It's a tough one [voice trailing off]. [M4]

Like the *Wanting to Disclose* parents, the struggle with unresolved grief and loss brought about by infertility and in particular the maternal loss of genetic lineage remained a barrier.

These painful memories appeared to hold back the disclosure process for both M3 and M4 -- especially when compounded with the fear about how their children would perceive them after

disclosing. This concern fueled questions about how to tell the children. M4 returned to this concern several times in her interview:

I think it is just, you know, we grieve our loss [of biological motherhood] sometimes and feel inadequate ... You do wonder how their reaction would be. [M4]

[I] don't know how to say it [informing children about OD]. And how will the children react to it? You know, how are they going to be affected by this? [M4]

In contrast to M4's feelings of grief, F4 had another reason for not disclosing to his sons albeit his reason centered on how his sons would perceive him during middle childhood after disclosing. He explained,

And I feel like right now if we were to sit them down on the couch and tell them, they wouldn't get it. And I don't mean that badly – its – they might think that daddy slept with another woman to have a baby. [pauses] That's what I think – I think I know they would think that. Like a mommy is a mommy – but daddy had tried with somebody else to have me. I think that would be their non-educated answering even if we explained it – with graft charts. [F4]

M3 also expressed concerns about the developmental readiness of her child and said, “He doesn't even know where children come from.” Another barrier the parents perceived was overcoming concerns about how to navigate family issues that would result from disclosure such as half-siblings. “And how would that work?” M4 voiced.

Three of the four *Conflicted about Disclosure* parents expressed both interpersonal and inter-couple stress and conflict about their decision not to disclose. For example, F4 talked about the importance of parents teaching honesty and not keeping secrets from their children. He also discussed his concerns about his children finding out unintentionally from a former brother in-law. He explained,

He [former brother-in-law] knows the basics, that's stressful... That's a stressor to both of us, to each other. [F4]

Part of the parents' reasons for secrecy surrounded the perceived lack of a benefit to their children's knowing about their OD origins and a perception that family functioning was high.

Lack of a benefit about knowing was expressed by M3 and M4 during pregnancy and remained consistent at the 12-year follow-up. For example, M3 said at the follow up, “He [son] having knowledge [about OD], is it going make any difference in his life now? Not really.” Discussed by these parents more so than the *Wanting to Disclose* parents was the perception that the family was functioning well and in particular the children were performing at a high level (e.g., academically and athletically). F3 said,

And, um, he, um, and because he's so intelligent—you know he has a very high IQ—he, he, he, um, even when he doesn't agree with you, he will logic with you point to point and— And his points all make sense ... he's the whole package. He's really a—you know, so many people say to us, like, he's going to be somebody. I'm telling you, he's really— He's really blessed. He's really blessed, yeah.

Not Planning to Disclose

Of the families in this cohort, Family 5 was the only family that used a known donor, which was M5's sister. M5's initial disclosure decision made during her OD pregnancy was not to disclose because of a mutually agreed upon contract between M5 and her sister. Yet, in one of the first sentences M5 voiced at the 12-year follow-up interview was:

I just – I don't know even how I would explain it to my kids. Do *you* know? Do they have any advice for [disclosure to children]? [M5]

As the interview progressed, M5 expressed inner tensions and concerns about whether to inform her now two children (ages 9 & 11 years) about their OD origins. M5 grappled not only with telling her children about their true origins but also with whether to divulge information about the identity of the donor (i.e., the children's aunt). F5 discussed little about the disclosure process in his interview but what he did state was, “[It's] kind of a scary thing that we don't think about or talk very often.” He went on to say,

I would hate to get it [disclosure] to a situation where for some reason you know they did find out and they are mad at us because we never told them. You know I don't ever want that to happen but I you know it's one of these things we don't discuss at all I mean there's only four people that know actually...and we are going to keep it that way. [F5]

In contrast, M5 talked about disclosure at length as she articulated personal barriers and concerns about disclosing. At the follow-up, a major barrier to disclosing for M5 was how the information would impact her children and their relationship with her. This concern, coupled with a recent “falling-out” between M5 and her donor sister added to her disclosure conundrum and tension.

M5 stated:

I think because of the unique situation [known donation], I’m afraid that giving her [daughter, age 11] that bit of unique information that as she gets older and as maybe people you know say things like, there’s a lot of people who will say, “Oh you’re just like Aunt Pam” or “You look a lot like her.” I just don’t think I want that to get in her head you know ... I’m afraid if I give a little bit [of information] she would [want more information], yeah I just, *not right now for her*. Maybe at 6 if I had told her at 6 it would’ve been completely different.... Maybe if someday if Elizabeth were to go through this [infertility] herself I would tell her then and I wouldn’t necessarily tell her who [the donor is] but honestly I mean I think she would ... figure it out. [M5]

Regarding disclosure to her son, M5 said: “I think that for Declan, I honestly think that it would break his heart. [pauses, and voice trails off] ... I don’t know maybe I don’t give my kids enough credit.”

M5 went on to state other barriers to disclosure were the uncertainty about how disclosure would or could change the existing family structures and the relationships between her and her sister’s family members, which she expressed both during pregnancy and again at the follow-up (e.g., would her children’s cousins remain cousins or would they become half-siblings?). M5 and F5 also expressed unresolved grief and recalled the emotional toll OD treatment took on them personally and in their marital relationship (“It got to the point where [pauses] and it was tough on our relationship.” [F5]). M5, like all mothers in the study, spoke about her fear that disclosing could cause her children to view her as other than their mother. She said, “I don’t want them to not like ever think of me as their mom” [M5], which posed a challenge for M5 and served to maintain her stance about not to disclose.

Having Disclosed

Only one family (Family 6) intended to disclose during the OD pregnancy and followed through and informed their twin 11-year-old daughters about their conceptual origins. The parents, who were interviewed separately at the 12-year follow-up and were experiencing recent marital separation, reported the twins were first informed about their OD conception at “about” age five. Noteworthy, during pregnancy, these parents chose to tell only close family and several friends about their use of OD. When probed at the follow-up interview about their reasons for disclosing, F6 summed up the parents’ thoughts on disclosure and said,

Well, I just think that if you’re, if you’re keeping secrets or you’re ashamed of, of how you produce your children, whether you’re willing to admit it or not, the closeness of it points to only thing -- you’re embarrassed, you’re ashamed, you, you, you want it to be a secret. And I think that’s extremely unhealthy. I know, I have a friend who wasn’t told that she was adopted until she was 16, and it created a lot of problems for her. [F6]

When probed about why they as parents were able to disclose and other parents could not, the parents reported they always agreed on disclosure and “because it’s part of our family story.” [F6] During pregnancy, M6 had said, “I think that you have to do it [disclose] from the very beginning. And you have to make it part of the family dynamic and you have to kind of weave it into their family history and story.” F6 also added that part of the key to disclosing was providing ongoing support for his wife by recognizing and assuring his wife’s need to be viewed as the “real” mother. He explained,

Never let your wife feel like, uh ... like she’s missing something, or [she’s] not, or that she’s not their mom, or anything negative like that at all, *ever*. [F6]

M6 discussed the trigger for disclosure was when her children began to form an understanding about pregnancy and the birth of babies and asked her, “When we were in mommy’s tummy did we _____ [pauses] blank?” Questions about pregnancy and birth by her children thus served as

the impetus for M6's disclosure to her children. In contrast, F6 did not recall a trigger per se, rather he recommended that other parents,

Take a casual moment, like if you're in the bedroom putting the, the kids to sleep, or you're just, you've got some downtime with them, and you're just kind of hanging out. The parent who's the responsible one and their teacher needs to bring it up. They need to initiate the conversation. There's never going to be a, a time where – I mean, it's going to be very seldom [that children ask specifically about conception]. They [parents] just need to bring it up. And they need to bring it up early so the kids have that understanding from the beginning. I – and, and, um, as they get older, you can tell them more age-appropriate things. [F6]

F6 went on to describe the language for how he told his children,

So we just said something like, you know, "Hey, girls, I want to tell you something really, really cool that you don't know. Do you want to hear something?" And they're always going to say, "Yeah, what is it?" [F6 went on to say:] "But for some reason, you know, mommy's eggs weren't able to make baby. And so mommy and daddy wanted you *so much*, and loved you *so much*, that we actually were able to find somebody that was willing to donate *just* their eggs. And mommy still had you in her tummy, and you know, everything else was exactly the same. But for the egg part of it, you know, we were able to find somebody that, that, uh, was able to help us because *we loved you so much* and *wanted you so much*." And I think that's important to stress that part [about loving them and wanting them]. [F6]

An important point about disclosure was revealed by M6 regarding her children's reaction to the information. She said, "Their reaction was so, so – *minimal* – that I thought to myself – why was I so anxious about telling them?" She did clarify at a later point in the interview, however, that her children asked "Are you our mother?" and she then calmly explained to them that she, in fact, was their "*real* mom."

Children's Perceptions of Family Composition

The two children who had not been told of their conceptual origins drew families that were consistent with the existing family composition portrayed by their parents (i.e., mother, father, child). The children did not describe any deviation of their family's composition nor any genetic discrepancies that might indicate knowledge or suspicion of OD during the interview process. Noteworthy, the majority of parents ($n = 4$ families) who had not informed their

child(ren) of their conceptual origins opted to deny permission for their children to participate in the draw-and-tell interview process. The two children who had been told of their conceptual origins also drew pictures that were consistent with the existing family composition. There was no mention of the OD.

Discussion

In view of the growing trend toward openness and the parents' initial disclosure decisions made during the OD pregnancy (i.e., only one family in our initial cohort intended not to disclose the OD to their children during pregnancy; 43% intended to disclose, and 43% were undecided), we were surprised that only one family in the cohort had disclosed the use of OD to their children at the 12-year follow-up. Moreover, the one family in the cohort that withdrew from participation had also not disclosed the OD to their children. Thus, our 12-year follow-up actual disclosure rate is 14% across all seven initial cohort families, lower than the retrospectively collected 23% disclosure rate among OD parents from the west coast region (California) (mean age of oldest OD children = 3.5 years) (Shehab et al., 2008) or the 43% disclosure rate of OD parents from the east coast region (New York/New Jersey area) (mean age of OD children = 13 years) (Applegarth et al., 2016) within the US. To our knowledge, this is the first study that has followed a cohort of families for 12 years after initial OD treatment and reported initial disclosure decisions made during the OD pregnancy and actual disclosure rates at middle childhood in the US.

Other important findings were that most of our parents (4 of the 6 families), apart from the two *Wanting to Disclose* parents, adhered to their initial disclosure decision voiced during pregnancy. Daniels et al. (2009) has also reported that when sperm donation parents were queried about their disclosure decisions when their children were 1 to 6 years of age, the parents'

initial decision regarding disclosing or not disclosing was maintained over 14 years. Yet, we did detect subtleties among two families in our cohort for conditions for disclosure at the 12-year follow-up. M5 clearly moved to considering disclosure under certain conditions (e.g., “Maybe if someday if Elizabeth were to go through this [infertility] herself I would tell her then.”). This finding and in conjunction with F4 who verbalized his sons’ developmental readiness as a condition for disclosure (e.g., “they wouldn’t get it [at middle-childhood] ...they might think that daddy slept with another woman”) represents a shift in reasoning not seen in the initial interviews. Whether this shift leads to disclosure in these families is unknown but it does indicate a more open stance regarding disclosure. The ‘condition’ set by these parents regarding disclosure extends the research on parental disclosure strategies described by Mac Dougall and colleagues (2007) whereby parents who use a *right-time* strategy for disclosure typically attach a prerequisite condition (usually a time when the child will be most receptive to disclosure). The condition verbalized by M5 and F4 thus indicates movement toward disclosure that may represent a break-through step in the disclosure process. Caution is warranted as our sample is small and some right-time parents have allowed the condition to pass without disclosing or the condition does not appear and disclosure does not occur (Applegarth et al., 2016; Mac Dougall et al., 2007). Follow-up research that examines parental use of conditions for disclosure (e.g., what types of conditions do parents set? When do they set them? Which types lead to disclose/non-disclosure? And why?) would advance understanding about disclosure.

Our findings support many of the underlying factors that contribute to parents’ decision processes about disclosure (e.g., perceptions of personal shame about infertility and/or social stigma, differing opinions within the couple dyad, beliefs about the child’s right to know versus a perceived benefit to telling the child) (Indekeu et al., 2013). Because the extensive review by

Indekeu et al. (2013) called for use of an explanatory theoretical framework to situate studies examining disclosure decisions, the four parental disclosure patterns identified in this study can be further delineated using the Decision-Making Process Model or DMPM. The DMPM has described couples' decision processes related to preimplantation genetic diagnosis (Hershberger et al., 2012) and young women's decisions about fertility preservation following a diagnosis of cancer (Hershberger, Finnegan, Altfeld, Lake, & Hirshfeld-Cytron, 2013; Hershberger, Sipsma, Finnegan, & Hirshfeld-Cytron, 2016). There are five interrelated dimensions within the DMPM: contextual influences (e.g., age, socioeconomic status), cognitive appraisals (e.g., risks, financial costs), emotional responses (e.g., joy, fear), moral judgements (e.g., opinion/evaluation of principles of value or desirability), and decision partners (e.g., influence of intimate partner or healthcare professionals). In Table 2, the qualitative codes within the parental disclosure patterns are aligned within the DMPM dimensions to provide an exemplar of a comparative theoretical structure.

What we did not find in our initial interviews during pregnancy compared to the follow-up interviews were the parents' heightened emphasis on concerns surrounding the children. As shown in Table 2, all of our families, including Family 6 who disclosed, expressed concern over how the children would react to knowledge of OD. The increased emphasis on the children, especially the children's reaction to a donor, was also reported by Lycett et al. (2005) among sperm donation parents with children aged 4 to 8 years – near the ages of the children in our sample. Our finding and those of Lycett et al. provide awareness for the nuanced concerns parents have about disclosure as their children approach or are in middle childhood. Another noteworthy finding was parents' remarks about how early parenthood responsibilities interfered

with their ability to carry out or even discuss disclosure with their partners, which has important implications for clinicians that provide education and counseling to intended OD parents.

Unresolved grief, stemming from infertility, was prevalent in many of the families (see Table 2) and appeared to exacerbate the fear that an unfavorable reaction by the children about OD would bring emotional and psychological pain that the family could not withstand, especially for the OD mothers. Indekeu (2013) mentions coping with infertility in terms of gender differences, with men more likely to cope with infertility by distancing themselves from the problem. Our findings revealed a deeper issue with unresolved grief from both fathers and mothers that impacts the disclosure decision especially in relation to children's reaction and acceptance of their parents. It was as if the parents could not withstand further "trauma" by enduring a disclosure that would cause harm to their child or harm to their child's relationship with the parents. In reviewing the nuances in the data, parents tended to be less concerned about shame and stigma, although it remained a concern, but more significant was the unresolved and lingering grief by parents, especially the mothers at middle childhood.

Thus, clinicians should consider assessing for unresolved grief when counseling parents about disclosure. Researchers have advocated for additional counseling for parents (Applegarth et al., 2016; Söderström-Anttila et al., 2010) yet a goal should be to ensure that counseling is achieving the desired outcome of a healthy disclosure for *Wanting to Disclose* parents that minimizes parental grief and maximizes the parent-child relationship. An important next step for future longitudinal research would be to target *Wanting to Disclose* parents at pregnancy to ascertain parental success and challenges to disclosure in view of our findings about lingering grief.

Many of the OD parents voiced concerns about how and when to tell their children. Especially challenging for parents was how to disclose when there were OD children of various ages in the family. Prior research about whether disclosure is enhanced or more challenging in families with donor conceived children of multiple ages is inconclusive (Indekeu et al., 2013). Our finding trend toward more challenging as the *Having Disclosed* family, Family 6, had twins (age 11 years) while the two *Wanting to Disclose* families had OD children of multiple ages. In one of the few studies examining disclosure in families where there were two or more children, parents were less likely to disclose the sperm donation origins to their children compared to families with one child (Lycett et al., 2005). The investigators suggested that parents with an older child might already have made the decision not to disclose the donor conception to their oldest child and then maintained disclosure consistency with the subsequent child(ren). Our findings elucidate another reason: parents grapple with how to disclose because of the added complexity involved with children of multiple ages (e.g., should the children be told at the same time? If so, how does the developmental stages of the children impact the language used? Or, should the older child be told first and then delay telling the younger child until he/she reaches the age of when the first child was told? If so, what instructions should the parent give the older child to prevent him/her from telling the younger child, if any?).

Parents in our *Conflicted about Disclosure* and *Not Planning to Disclose* families also voiced significant concern about their child's/children's reaction to OD as it extended into family relationships with donors and any half-siblings. Research in this area is limited, however, parents who decided to establish contact with their children's donor or half-siblings typically report positive experiences (Freeman, Jadv, Kramer, & Golombok, 2009) as did anonymous donors who decided to establish contact with their donor offspring (Jadv, Freeman, Kramer, &

Golombok, 2011). Yet, this appears to be an important linchpin for many parents in their decision about disclosure/non-disclosure.

The strong statements by F3 about how well his child was performing combined with his strong stance for secrecy, is unexplored in the literature. We now question whether children's academic or other performance (e.g., behavioral, athletic, musical talent) at middle childhood impacts parental disclosure. It could be that parents with an exceptionally gifted academic or other high performing OD child find disclosure less appealing, as in the case of F3. In these families, parents may be concerned that disclosure might upset the child and interfere with their performance. Another explanation is that disclosure may bring the added parental challenge of navigating unwanted social stigma by acknowledging the child's high performance could be the result of the genetic inheritance from the donor. Conversely, in families where children perform poorly, academically or in other areas, parents may be more likely to disclose to deflect responsibility onto the donor for the child's poor performance. Although children's performance at middle childhood has not been specifically linked to parents' decision processes about disclosure in previous literature, in a seminal report, Becker, Butler, and Nachtigall (2005) define "resemblance talk" as a child's *physical* similarities to parents or other family members, a concept that remains important in present-day disclosure decisions (Indekeu, D'Hooghe, Daniels, Dierickx, & Rober, 2014; Wong, 2017). Our findings could be the basis for a new concept that impacts disclosure decisions, "performance talk" that emerges as a child grows into middle childhood and possibly beyond.

Using our novel Draw-and-Tell Conversation method, we did not find that children of middle childhood were aware of any discrepancies in their family's composition or with genetic traits. Because the sample of children was small, this finding merits caution as the majority of

non-disclosing parents did not provide permission for their children to participate. Although the two children who had not been told were unaware of family composition or genetic trait discrepancies, it does not mean other children of this age would be without suspicion. In the US science curriculum – *Next Generation Science Standards* – children receive basic education about biology and life sciences in the first grade, with specific genetics curriculum introduced in the third grade (National Research Council, National Science Teachers Association, American Association for the Advancement of Science, & Achieve, 2017). The timing of children’s genetics education, along with our findings and those of Daniels et al. (2011) where adolescents at 16 years questioned their family’s composition, suggests that middle childhood may be a viable window for healthy disclosure before children begin to raise genetically-based questions about their family’s composition. Future research that fully examines the effects on children regarding parental disclosure during middle childhood would provide much needed information.

The limitations of the study include the self-selection of the participants and the lack of racial, ethnic, and geographical diversity among families. The small sample size and qualitative nature of the study merits caution; however, our findings provide clinicians and researchers with insights and nuances that shed light on how modern OD families in the US navigate the decision to disclose or not to disclosure OD to their children from the point of pregnancy to middle childhood. We acknowledge our clinical experiences with OD families may have shaped our interpretation of the qualitative findings. Additionally, our interviews at pregnancy and at the 12-year follow-up may have impacted parents’ decisions, although the parents gave no indication of such influence at the 12-year follow-up. Only future research can determine if the *Wanting to Disclose* parents eventually disclose and if our findings and insights about M5’s and F4’s “conditions” for disclosure result in actual disclosure.

The strengths of the study are the prospective design, the high response rate, the ability to capture disclosure processes during the cohort's same family stage (i.e., middle childhood), and from both parents in our families as well as during an equivalent sociopolitical milieu. These advantages allow us to be more confident that the similarities and differences captured across and within families represents real-time disclosure processes. Another strength, although limited due to sample size, was the innovative use of the Draw-and-Tell Conversation interview that demonstrated that children who were unaware of their OD did not harbor knowledge or suspicion of it at middle childhood. We encourage future researchers to seek a larger and more diverse cohort to add to the small albeit growing body of research regarding family disclosure in donor conceptions.

In conclusion, although our sample size is small, we are the first to report initial disclosure decisions made during the OD pregnancy and actual disclosure decisions over the course of 12 years post-OD treatment in a prospective sample of OD families in the US. Four parental disclosure patterns were identified at 12 years: *Wanting to Disclose*, *Conflicted about Disclosure*, *Not Planning to Disclose*, and *Having Disclosed*. Only one family (Family 5) in our cohort initially decided during pregnancy not to disclose the OD to their future children. In actuality at 12 years, only one family (Family 6) from our cohort had disclosed the OD origins to their two twins at about age five. Two of our families that reported a desire to inform their children during pregnancy had not done so and our two families that were undecided during pregnancy remained ambivalent about disclosure. We did detect more parental acceptance of disclosure in two of our families (one undecided during pregnancy, one against disclosure during pregnancy). The two children that had not been told of their OD origins and completed our novel draw-and-tell interview did not report discrepancies of family composition; however, most

parents who had not disclosed OD to their children were reluctant to allow their children to participate. As suggested by Indekeu et al. (2013), we provided an exemplar of a theoretical structure, the DMPM, that can be used for comparing decision processes of parents across the four parental decision patterns. Our findings point to a need for targeted research that can assist *Wanting to Disclose* parents with disclosure and *Conflicted about Disclosure* parents with strategies to optimize decision making. Steps toward a family-centric approach in clinical practice should include assessing OD parents for unresolved grief related to infertility and loss of biological motherhood as it may likely impact parent's ability to disclose and their disclosure decisions.

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Declaration of Interest

The authors declare no conflicts of interest.

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Note

Research about family's OD disclosure is sensitive. Some demographic data have been disguised to mitigate unintentional disclosure.

References

- Applegarth, L. D., Kaufman, N. L., Josephs-Sohan, M., Christos, P. J., & Rosenwaks, Z. (2016). Parental disclosure to offspring created with oocyte donation: Intentions versus reality. *Human Reproduction*, 31(8), 1809-1815. doi:10.1093/humrep/dew125
- Ayres, L., Kavanaugh, K., & Knafl, K. A. (2003). Within-case and across-case approaches to qualitative data analysis. *Qualitative Health Research*, 13(6), 871-883. doi:10.1177/1049732303013006008
- Becker, G., Butler, A., & Nachtigall, R. D. (2005). Resemblance talk: A challenge for parents whose children were conceived with donor gametes in the US. *Social Science and Medicine*, 61(6), 1300-1309. doi:10.1016/j.socscimed.2005.01.018
- Beeson, D. R., Jennings, P. K., & Kramer, W. (2011). Offspring searching for their sperm donors: How family type shapes the process. *Human Reproduction*, 26(9), 2415-2424. doi:10.1093/humrep/der202
- Blake, L., Casey, P., Jadv, V., & Golombok, S. (2014). 'I was quite amazed': Donor conception and parent-child relationships from the child's perspective. *Children & Society*, 28(6), 425-437. doi:10.1111/chso.12014
- Blake, L., Jadv, V., & Golombok, S. (2014). Parent psychological adjustment, donor conception and disclosure: A follow-up over 10 years. *Human Reproduction*, 29(11), 2487-2496. doi:10.1093/humrep/deu231
- Crawshaw, M., Adams, D., Allan, S., Blyth, E., Bourne, K., Brugge, C., . . . Zweifel, J. E. (2017). Disclosure and donor-conceived children. *Human Reproduction*, 32(7), 1535-1536. doi:10.1093/humrep/dex107

- Daniels, K. (2007). Donor gametes: anonymous or identified? *Best Practice & Research: Clinical Obstetrics and Gynaecology*, 21(1), 113-128.
doi:10.1016/j.bpobgyn.2006.09.010
- Daniels, K., Gillett, W., & Grace, V. (2009). Parental information sharing with donor insemination conceived offspring: A follow-up study. *Human Reproduction*, 24(5), 1099-1105. doi:10.1093/humrep/den495
- Daniels, K. R., Grace, V. M., & Gillett, W. R. (2011). Factors associated with parents' decisions to tell their adult offspring about the offspring's donor conception. *Human Reproduction*, 26(10), 2783-2790. doi:10.1093/humrep/der247
- de Melo-Martín, I. (2014). The ethics of anonymous gamete donation: Is there a right to know one's genetic origins? *Hastings Center Report*, 44(2), 28-35. doi:10.1002/hast.285
- de Melo-Martín, I. (2016). How best to protect the vital interests of donor-conceived individuals: Prohibiting or mandating anonymity in gamete donations? *Reproductive BioMedicine and Society Online*, 3, 100-108. doi:10.1016/j.rbms.2017.01.003
- Driessnack, M. (2009). Using the Colored Eco-Genetic Relationship Map with children. *Nursing Research*, 58(5), 304-311. doi:10.1097/NNR.0b013e3181b49928
- Driessnack, M., & Gallo, A. M. (2013). Children 'draw-and-tell' their knowledge of genetics. *Pediatric Nursing*, 39(4), 173-180.
- Ethics Committee of the American Society for Reproductive Medicine. (2004). Informing offspring of their conception by gamete donation [Supplement 1]. *Fertility and Sterility*, 82, S212-S216. doi:10.1016/j.fertnstert.2004.05.009

- Ethics Committee of the American Society for Reproductive Medicine. (2018). Informing offspring of their conception by gamete or embryo donation: An Ethics Committee opinion. *Fertility and Sterility*, 109(4), 601-605. doi:10.1016/j.fertnstert.2018.01.001
- Freeman, T., Jadva, V., Kramer, W., & Golombok, S. (2009). Gamete donation: Parents' experiences of searching for their child's donor siblings and donor. *Human Reproduction*, 24(3), 505-516. doi:10.1093/humrep/den469
- Golombok, S. (2017). Disclosure and donor-conceived children. *Human Reproduction*, 32(7), 1532-1536. doi:10.1093/humrep/dex104
- Golombok, S., Brewaeys, A., Giavazzi, M. T., Guerra, D., MacCallum, F., & Rust, J. (2002). The European study of assisted reproduction families: The transition to adolescence. *Human Reproduction*, 17(3), 830-840. doi:10.1093/humrep/17.3.830
- Greenfeld, D. A. (2008). The impact of disclosure on donor gamete participants: Donors, intended parents and offspring. *Current Opinion in Obstetrics and Gynecology*, 20(3), 265-268. doi:10.1097/GCO.0b013e32830136ca
- Harper, J. C., Kennett, D., & Reisel, D. (2016). The end of donor anonymity: How genetic testing is likely to drive anonymous gamete donation out of business. *Human Reproduction*, 31(6), 1135-1140. doi:10.1093/humrep/dew065
- Hershberger, P. (2004). Recipients of oocyte donation: An integrative review. *Journal of Obstetric, Gynecologic, & Neonatal Nursing*, 33(5), 610-621. doi:10.1177/0884217504268524
- Hershberger, P., Klock, S. C., & Barnes, R. B. (2007). Disclosure decisions among pregnant women who received donor oocytes: A phenomenological study. *Fertility and Sterility*, 87(2), 288-296. doi:10.1016/j.fertnstert.2006.06.036

- Hershberger, P. E. (2007). Pregnant, donor oocyte recipient women describe their lived experience of establishing the "family lexicon". *Journal of Obstetric, Gynecologic, & Neonatal Nursing*, 36(2), 161-167. doi:10.1111/j.1552-6909.2007.00128.x
- Hershberger, P. E., Gallo, A. M., Kavanaugh, K., Olshansky, E., Schwartz, A., & Tur-Kaspa, I. (2012). The decision-making process of genetically at-risk couples considering preimplantation genetic diagnosis: Initial findings from a grounded theory study. *Social Science & Medicine*, 74(10), 1536-1543. doi:10.1016/j.socscimed.2012.02.003
- Hershberger, P. E., Finnegan, L., Altfeld, S., Lake, S., & Hirshfeld-Cytron, J. (2013). Toward theoretical understanding of the fertility preservation decision-making process: Examining information processing among young women with cancer. *Research and Theory for Nursing Practice*, 27(4), 257-275. doi:10.1891/1541-6577.27.4.257
- Hershberger, P. E., & Kavanaugh, K. (2008). Enhancing pregnant, donor oocyte recipient women's health in the infertility clinic and beyond: A phenomenological investigation of caring behaviour. *Journal of Clinical Nursing*, 17(21), 2820-2828. doi:10.1111/j.1365-2702.2007.02211.x
- Hershberger, P. E., Sipsma, H., Finnegan, L., & Hirshfeld-Cytron, J. (2016). Reasons why young women accept or decline fertility preservation after cancer diagnosis. *Journal of Obstetric, Gynecologic, & Neonatal Nursing*, 45(1), 123-134. doi:10.1016/j.jogn.2015.10.003
- Hsieh, H. F., & Shannon, S. E. (2005). Three approaches to qualitative content analysis. *Qualitative Health Research*, 15(9), 1277-1288. doi:10.1177/1049732305276687

- Indekeu, A., D'Hooghe, T., Daniels, K. R., Dierickx, K., & Rober, P. (2014). 'Of course he's our child': Transitions in social parenthood in donor sperm recipient families. *Reproductive BioMedicine Online*, 28(1), 106-115. doi:10.1016/j.rbmo.2013.09.021
- Indekeu, A., Dierickx, K., Schotsmans, P., Daniels, K. R., Rober, P., & D'Hooghe, T. (2013). Factors contributing to parental decision-making in disclosing donor conception: A systematic review. *Human Reproduction Update*, 19(6), 714-733. doi:10.1093/humupd/dmt018
- International Federation of Fertility Societies. (2013). *IFFS surveillance 2013*. Retrieved from http://c.ymcdn.com/sites/www.iffss-reproduction.org/resource/resmgr/iffss_surveillance_09-19-13.pdf
- Isaksson, S., Sydsjö, G., Skoog Svanberg, A., & Lampic, C. (2012). Disclosure behaviour and intentions among 111 couples following treatment with oocytes or sperm from identity-release donors: Follow-up at offspring age 1-4 years. *Human Reproduction*, 27(10), 2998-3007. doi:10.1093/humrep/des285
- Ishihara, O., Adamson, G. D., Dyer, S., de Mouzon, J., Nygren, K. G., Sullivan, E. A., . . . Mansour, R. (2015). International committee for monitoring assisted reproductive technologies: World report on assisted reproductive technologies, 2007. *Fertility and Sterility*, 103(2), 402-413 e411. doi:10.1016/j.fertnstert.2014.11.004
- Jadva, V., Freeman, T., Kramer, W., & Golombok, S. (2009). The experiences of adolescents and adults conceived by sperm donation: Comparisons by age of disclosure and family type. *Human Reproduction*, 24(8), 1909-1919. doi:10.1093/humrep/dep110

- Jadva, V., Freeman, T., Kramer, W., & Golombok, S. (2011). Sperm and oocyte donors' experiences of anonymous donation and subsequent contact with their donor offspring. *Human Reproduction*, 26(3), 638-645. doi:10.1093/humrep/deq364
- Klock, S. C., & Greenfeld, D. A. (2004). Parents' knowledge about the donors and their attitudes toward disclosure in oocyte donation. *Human Reproduction*, 19, 1575-1579. doi:10.1093/humrep/deh289
- Lalos, A., Gottlieb, C., & Lalos, O. (2007). Legislated right for donor-insemination children to know their genetic origin: A study of parental thinking. *Human Reproduction*, 22(6), 1759-1768. doi:10.1093/humrep/dem063
- Lycett, E., Daniels, K., Curson, R., & Golombok, S. (2004). Offspring created as a result of donor insemination: A study of family relationships, child adjustment, and disclosure. *Fertility and Sterility*, 82(1), 172-179. doi:10.1016/j.fertnstert.2003.11.039
- Lycett, E., Daniels, K., Curson, R., & Golombok, S. (2005). School- aged children of donor insemination: A study of parents' disclosure patterns. *Human Reproduction*, 20(3), 810-819. doi:10.1093/humrep/deh703
- Mac Dougall, K., Becker, G., Scheib, J. E., & Nachtigall, R. D. (2007). Strategies for disclosure: How parents approach telling their children that they were conceived with donor gametes. *Fertility and Sterility*, 87(3), 524-533. doi:10.1016/j.fertnstert.2006.07.1514
- McGee, G., Brakman, S.-V., & Gurmankin, A. D. (2001). Gamete donation and anonymity: Disclosure to children conceived with donor gametes should not be optional. *Human Reproduction*, 16(10), 2033-2038. doi:10.1093/humrep/16.10.2033

- National Research Council, National Science Teachers Association, American Association for the Advancement of Science, & Achieve. (2017). *Next Generation Science Standards: For States, by States*. Retrieved from <https://www.nextgenscience.org/>
- Pasch, L. A., Benward, J., Scheib, J. E., & Woodward, J. T. (2017). Donor-conceived children: The view ahead. *Human Reproduction*, 32(7), 1534. doi:10.1093/humrep/dex105
- Patton M. Q. (2015). *Qualitative research & evaluation methods* (4th ed.). Thousand Oaks, CA: Sage.
- Pennings, G. (2017). Disclosure of donor conception, age of disclosure and the well-being of donor offspring. *Human Reproduction*, 32(5), 969-973. doi:10.1093/humrep/dex056
- Phillips, A. M. (2016). 'Only a click away - DTC genetics for ancestry, health, love...and more: A view of the business and regulatory landscape'. *Applied & Translational Genomics*, 8, 16-22. doi:10.1016/j.atg.2016.01.001
- Raes, I., Ravelingien, A., & Pennings, G. (2016). Donor conception disclosure: Directive or non-directive counselling? *Journal of Bioethical Inquiry*, 13(3), 369-379. doi:10.1007/s11673-015-9686-9
- Readings, J., Blake, L., Casey, P., Jadv, V., & Golombok, S. (2011). Secrecy, disclosure and everything in-between: Decisions of parents of children conceived by donor insemination, egg donation and surrogacy. *Reproductive BioMedicine Online*, 22(5), 485-495. doi:10.1016/j.rbmo.2011.01.014
- Sabatello, M. (2015). Regulating gamete donation in the U.S.: Ethical, legal and social Implications. *Laws*, 4(3), 352-376. doi:10.3390/laws4030352

- Scheib, J. E., Riordan, M., & Rubin, S. (2005). Adolescents with open-identity sperm donors: Reports from 12-17 year olds. *Human Reproduction*, 20(1), 239-252.
doi:10.1093/humrep/deh581
- Shehab, D., Duff, J., Pasch, L. A., Mac Dougall, K., Scheib, J. E., & Nachtigall, R. D. (2008). How parents whose children have been conceived with donor gametes make their disclosure decision: Contexts, influences, and couple dynamics. *Fertility and Sterility*, 89(1), 179-187. doi:10.1016/j.fertnstert.2007.02.046
- Söderström-Anttila, V., Sälevaara, M., & Suikkari, A. M. (2010). Increasing openness in oocyte donation families regarding disclosure over 15 years. *Human Reproduction*, 25(10), 2535-2542. doi:10.1093/humrep/deq194
- Van Parys, H., Wyverkens, E., Provoost, V., De Sutter, P., Pennings, G., & Buysse, A. (2016). Family communication about donor conception: A qualitative study with lesbian parents. *Family Process*, 55(1), 139-154. doi:10.1111/famp.12112
- Wong, K. A. (2017). Donor conception and "passing," or; why Australian parents of donor-conceived children want donors who look like them. *Journal of Bioethical Inquiry*, 14(1), 77-86. doi:10.1007/s11673-016-9755-8
- Zadeh, S., Freeman, T., & Golombok, S. (2017). 'What does donor mean to a four-year-old?': Initial insights into young children's perspectives in solo mother families. *Children & Society*, 31(3), 194-205. doi:10.1111/chso.12181
- Zadeh, S., Jones, C. M., Basi, T., & Golombok, S. (2017). Children's thoughts and feelings about their donor and security of attachment to their solo mothers in middle childhood. *Human Reproduction*, 32(4), 868-875. doi:10.1093/humrep/dex016

Table 1. Interview Guide: Sample of Questions and Probes

Broad Open-Ended Question	Please tell me what it has been like for you to be a donor-egg recipient mom [or father] of a/an egg-donor child(ren) these past 12 years.
Follow-Up Question	As you think about your decision to tell or not tell your child 12 years ago and now, how has your decision about telling your child changed over time, if at all?
Follow-Up Question	What was your reasons for your decision to tell or not tell your child 12 years ago and what are your reasons now?
Probe (if not addressed)	What is the hardest part about making the decision to tell or not tell your child(ren) about their conceptual origins?
Probe (if not addressed)	How is your decision about disclosing similar or different from your partner?
Follow-Up Question	Is there anything else important about telling or not telling your child/children about their conceptual origins that we have not discussed? If so, can you tell me what it is?

Table 2. Exemplar: Parental Disclosure Patterns Aligned within the Dimensions of the Decision-Making Process Model (DMPM)

DMPM: FIVE INTERRELATED DIMENSIONS		FOUR PARENTAL DISCLOSURE PATTERNS			
	Code	<i>Wanting to Disclose</i>	<i>Conflicted about Disclosure</i>	<i>Not Planning to Disclose</i>	<i>Having Disclosed</i>
<i>Contextual Influences**</i>	Family* and age distribution of OD children	Family 1 Two children ages 8 & 11 Family 7 Three children, age 8 to 11	Family 3 One child age 11 Family 4 Two children, twins, age 11	Family 5 Two children, ages 9 & 11	Family 6 Two children, twins, age 11
	Donor Type	Anonymous	Anonymous	Known (mother's sister)	Anonymous
<i>Cognitive Appraisals</i>	Uncertainty about how and when to tell	How and when to tell children is unknown (including concern about how and when to tell with children of various ages).	How and when to tell is unknown.	How and when to tell children is unknown. However, one partner introduces idea of "conditional" disclosure in the future.	Told twins at age 5.
	Perception about whether child is "ready" to know OD origins	Questions whether children are cognitively and/or emotionally ready to understand OD origins.	Questions whether children are cognitively and/or emotionally ready to understand OD origins.	Questions whether child(ren) are cognitively and/or emotionally ready to understand OD origins.	Determined children were "ready" at age 5.
	Anticipated reaction of the child to OD information	Concerned children will not understand.	Perceives risk for children constructing an alternative conceptual story due to developmental stage and gender of the child, or, concerned children will not understand.	Determines OD knowledge would harm children.	Attempted to foster thoughts of OD as being "cool" and instilling the message of how wanted and loved the children were even prior to their birth.
	Perceptions of health and	Perceives family functioning as appropriate.	Perceives family functioning as high.	Perceives nuclear family functioning as appropriate or high;	Perceives family functioning as high.

	functioning of the family unit	Admits to not fully thinking through disclosure issue when facing or undergoing OD treatment.		relationship with sister/donor is strained.	
	Risk for unintentional disclosure to the children	Unintentional disclosure is perceived as a risk.	Unintentional disclosure is perceived as a risk and creates stress.	Creates tight limits regarding disclosure to others to minimize risk of unintentional disclosure.	Unintentional disclosure managed through telling children at age 5.
	Life experiences	Early parenting experience was demanding and exhaustively, thereby not allowing time to thoroughly think-through disclosure process. Experienced upheaval regarding the opening of an IVF clinic from religious leaders and friends.	One family has children from prior marriage.	Have contractual agreement with donor not to disclose.	Knew friend that was told of adoption at age 16, which was difficult for friend.
	Outward Resemblance	Children outwardly look like parents so disclosure is “easy” to conceal.	Children outwardly look like parents.	Children outwardly look like parents.	Children outwardly look like parents.
	Performance of child	Child’s performance ranges from average to above average.	Child’s performance is exceptionally high or average to above average.	Child’s performance ranges from average to above average.	Child’s performance ranges from average to above average.
Emotional Responses	Grief and loss regarding biological motherhood and	Ongoing grief related to loss of biological motherhood.	Ongoing grief related to loss of biological motherhood.	Ongoing grief related to loss of biological motherhood and painful memories related to enduring IVF treatment.	Dissipating grief and loss related to biological motherhood.

	enduring IVF treatment	Protecting self from extremely painful memories about infertility experience and for mothers, loss of biological motherhood.			Male partner stresses view that his wife always be regarded as the “real mother.”
	Fear of harming the mother-child, or wider family relationships	Fear that child’s reaction to OD would be harmful to child, mother, or family.	Fear that child’s reaction to OD would be harmful to child, mother, or nuclear family or wider family relationships (e.g., concerns about half-siblings and negative reaction to the child by extended family members).	Fear that child’s reaction to OD would be harmful to child, mother, or family or wider family relationships (e.g., cousins would become half-siblings).	Fear mitigated as “part of the family story” that lessened fear of impact of changes on parent-child and wider family relationships.
<i>Moral Judgments</i>	Parents have a responsibility to protect children	Struggles with parental role to protect child as disclosure would likely bring stigma to the child and family if OD known.	Protecting child and secondarily, family from stigma if OD known. Protecting current family relationships is paramount.	Protecting children by maintaining current family relationships are paramount. Protecting self from extremely painful memories about infertility experience and for mothers, loss of biological motherhood.	Protecting children is carried-out by helping children navigate novel family relationships and stigma.
	Benefit to child knowing about OD	Children would benefit by OD knowledge.	No perceived benefit to child in view of risks to family relationships.	Mother conflicted about whether beneficial or harmful to child but at present perceives disclosure would be harmful to child. Father perceives no benefit.	Children benefit by OD knowledge.

	Family secrets are harmful	Secrecy is not healthy; dishonesty is wrong.	Struggles over belief that honesty is of value in parent-child relationships.	Struggles over belief that honesty is of value in parent-child relationships.	Secrets are detrimental to the family.
	Children have a moral right to know conceptual origins	Children have a right to know OD. Yet, disclosure would likely bring harm or instability to family relationships.	Conflicted about children's right to know or believes that parent is able to make the best decision regarding disclosure to the child.	Children have a right to know if particular conditions arise whereas OD knowledge would be beneficial to him or her. Or, parent is able to make the best decision regarding disclosure to the child.	Children have a right to know OD.
<i>Decision Partners</i>	Inter-couple dynamics	Partners within the couple agree.	Partners within the couple disagree, or both partners are ambivalent about disclosure to child.	Partners within the couple essentially agree but conditions for future disclosure were noted in one partner.	Partners within the couple agree.

**Some *Contextual Influences* codes have been removed to maintain the anonymity of the families. *Family 2 withdrew from the study at the 12-year follow-up.