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# Disclosure Decisions among Pregnant Women who Received Donor Oocytes: A Phenomenological Study

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## Abstract

**Capsule—**Controversy surrounding disclosure among donor oocyte recipients is escalating worldwide. This in-depth analysis captures the voice of pregnant women who received donor oocytes and the factors that influence their decision to disclosure.

**OBJECTIVE—**Controversy surrounding disclosure among donor oocyte recipients is escalating worldwide, yet little research has sought to understand the disclosure experience of pregnant, donor oocyte recipient women. The purpose of this study was to provide an in-depth description of the disclosure experience, and identify factors that were significant to recipient women which influenced their reasoning as they formulated disclosure decisions.

**DESIGN—**Qualitative, naturalistic design using a phenomenological approach.

**SETTING—**The home or private office of the recipient woman.

**PARTICIPANTS—**Donor oocyte recipient women between 9 and 23 weeks gestation.

**RESULTS—**Disclosure decisions were influenced by multiple factors emerging from the women's values and beliefs and their social and cultural environment. Values and beliefs consisted of the right to know and the duty to protect. Social and cultural factors included social support, culture of the family, evolution of the social process, and personal testimonials. Women's age and selection of donor type are interrelated with disclosure decisions.

**CONCLUSIONS—**Disclosing women voiced the right of the child to know and perceived social and cultural factors as conducive to disclosure. Non-disclosing and undecided women emphasized protecting normative relationships, perceived social stigma, and were unable to identify a benefit to disclosing. Women's age and choice of oocyte donor should be considered when counseling recipient women.

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**Keywords**

decision making; disclosure; donor gametes; oocyte donation; pregnancy

## Introduction

Escalating discourse has centered on the question of whether or not donor gamete parents should inform their resulting child of their donor origins (1-6). Despite the significance of this issue and the ensuing sequela of events taking place, both from legislative and practice perspectives worldwide, a paucity of research examining disclosure among individuals involved in gamete donation exists. Most of the limited research in this area has focused on recipients of sperm donation (2,7-11). Less is known about donor oocyte recipient women even though the added complexity of obtaining an oocyte donor and the women's ability to experience pregnancy may significantly alter disclosure decisions.

Prior research examining the donor oocyte experience has focused on the disclosing patterns of recipients, which has varied among and within recipient groups. For example, Weil and associates questioned 41 anonymous oocyte recipients and reported 26% of the recipients plan to disclose the nature of the conception to their offspring (12), while Pettee and Weckstein found 88% of the 17 known donor recipient's queried plan to inform their child (13).

The variation in disclosure patterns among oocyte recipients lead to more recent research investigating relationships among recipients and the possible affect on disclosure decisions. In a study comparing the disclosure decisions of 64 anonymous oocyte recipients with 26 known (directed) oocyte recipients, Greenfeld and colleagues reported known donor recipients were more likely to tell the child (14). Yet, differing results have been reported. In a Finnish study, more anonymous oocyte recipients planned to inform the child than known oocyte recipients (15). Still another study found no significant difference among known and anonymous oocyte recipients toward telling the child (16).

Knowledge about the oocyte donor and the relationship this has on disclosure decisions has also been examined. Klock and Greenfeld reported a significant gender difference among 62 sets of oocyte donation parents with men, but not women, influenced by the amount of knowledge about the oocyte donor (17). In this study, men who knew more about the donor were more likely to indicate they have or are planning to inform the resulting child of their conceptual origins.

While several studies have examined specific oocyte recipient groups and their relationship to disclosure, two studies, completed from a qualitative perspective, sought to identify patterns or variables which influence disclosure among oocyte recipient families (18-19). Hahn and Craft-Rosenberg interviewed 31 anonymous donor oocyte recipient parents, whose children ranged in age from 6 months to 5 years (18). In this sample, beliefs and values such as the child's right to know most often influenced disclosing parents, no compelling reason to tell influenced non-disclosing parents, and undecided parents were influenced primarily by concerns about how and when to tell and their child's reaction to the information. A similar study was conducted in the United Kingdom, with 14 anonymous donor families and 3 known donor families, whose children were aged 3 to 8 years-old (19). Although disclosing parents reported the belief that the child has a right to know, they also planned to tell the child because they wanted to avoid accidental disclosure of the information by others. Non-disclosing and undecided parents were influenced most frequently by a desire to protect their child or the mother and a belief that there was no need to tell.

While the current literature examining disclosure decisions among donor oocyte recipients is expanding in scope, the wide range of patterns and often conflicting reported results leaves health care professionals without sufficient data to guide practice or policy. Therefore, in-depth qualitative research is needed to explore and understand donor oocyte recipients' experience regarding disclosure decisions from their perspective. Furthermore, no study has examined oocyte recipients' decision making exclusively during pregnancy, at which point in time recipients have recently or are in the midst of formulating disclosure decisions.

The purpose of this study was to provide an in-depth account of pregnant, donor oocyte recipient women's experience of using donor oocytes for conception. This paper focuses on describing the disclosure decisions of the recipient women, specifically on factors that influenced their reasoning, and ultimately their disclosure decisions, from a qualitative, naturalistic perspective. Data from the women's overall experience will be reported separately (20).

## Materials and Methods

This qualitative, naturalistic study used a phenomenological approach to obtain a richly detailed narrative description of the recipient women's disclosure decisions and the factors which influence those decisions. Other more structured research methods would not be able to capture the essence of the women's experience. For phenomenological studies, sequential in-depth interviews are conducted with each participant; therefore a small sample size of between six and eight participants is typically recommended (21). Also, because this research is highly sensitive and uses direct quotes, pseudonyms have been used when reporting the data.

After obtaining Institutional Review Board approval, patients were recruited from a large, urban infertility center located in the midwestern United States. The center was selected for recruitment because of the high volume and high pregnancy rates of oocyte donation.

Nine eligible, pregnant donor oocyte recipient women established contact with the principal investigator. Each woman was asked to participate in two in-depth, audiotaped, open-ended interviews and to complete a demographic questionnaire. If the woman agreed to participate, a mutually convenient date and time was selected for the first interview. Of the nine women initially agreeing to participate, one woman later telephoned the investigator prior to the onset of the first interview and withdrew from the study. This woman stated that she was reluctant to participate because she was not planning to inform her child about the nature of the conception and viewed participation as a potential mechanism for future accidental disclosure.

All of the remaining eight eligible women gave verbal and written informed consent prior to the first interview. A total of 16 interviews were completed, 2 by each participant. The setting for the interviews was the participant's home (81%) or a private office (19%). Fourteen of the interviews were completed during face-to-face sessions with the investigator and the remaining two interviews were completed via telephone. The length of the first interview sessions ranged from 58 to 108 minutes and the second interview sessions ranged from 15 to 52 minutes.

During the interviews, the investigator elicited the woman's description of the experience using an open-ended format and an interview guide. The interviews began with a broad introductory format where the individual's story is elicited, which is a successful strategy for interviews on sensitive topics (22-23). The interview guide (see Table I), based on the study's purpose and objectives, was generated from issues identified from a systematic and extensive review of the literature (24) and the clinical expertise of the investigators.

The second interview, recommended for interviews on sensitive topics (22,25), was completed with each participant to expand and clarify information described in the initial interview. Other

methods of data collection included a demographic questionnaire, completed by each participant, and field notes, recorded by the investigator.

The audiotape recordings of the interviews were transcribed verbatim and verified for accuracy. Then, the transcripts and field notes were analyzed using strategies articulated by Colaizzi for phenomenology (26). Data management included development of a case summary for each participant. Each of the eight case summaries contained information from the participant's transcripts, demographic data form, and the investigator's field notes. The case summaries served to ensure that the findings remained true to the context of the women's experience. Dependability and credibility of the descriptive analysis was validated through member checks, a form of participant verification of the analysis, and use of multidisciplinary reproductive experts in all phases of the study (26-27).

## Results

### Sociodemographics

All of the eight participants were Caucasian, married (mean = 6.5 years), and well educated. The predominant religion was Roman Catholic and the mean age of the women was 40.6 years (range = 33 to 46 years). Six of the women were in their first marriage and two women were in a second marriage. Only one of the participants had step-children and the remaining women and their partners were childless.

The length of infertility treatment varied from 1 to 5 years (mean = 2.3 years). All of the women were between 9 and 23 weeks of gestation and had conceived via oocyte donation, using their partner's sperm. Seven of the women selected an anonymous donor and one woman selected her sister as the donor. Five of women were experiencing twin pregnancies and three had singleton pregnancies.

### Broad Themes & Disclosure Patterns

Emerging from the disclosure data were two broad themes. The first theme, *engaging in selective disclosure*, was evident throughout each woman's experience as she selected the individuals whom she would tell, while also choosing how much of her infertility history to disclose to them. In many instances, the women would choose to tell only certain individuals about particular aspects of their treatment, such as their use of in vitro fertilization, but not their use of donor oocytes. One woman, who had told multiple individuals about her use of donor oocytes, surmised her reluctance to inform others as: "A couple of people you are more hesitant to tell the process of how you got pregnant. You just say you are pregnant maybe. But you've been through a lot of fertility, but you don't necessarily say it's a donor process.

Although all of the women were selective in their disclosure to others, the degree of their selectivity and openness varied. Three women were extremely open and informed multiple individuals about their infertility treatment and their use of donor oocytes. Two women informed several close family members and close friends about their experience and treatment. The three remaining women had informed three to four close family members only and when they informed these family members they requested that they keep the information private as they were not planning on divulging this information to any other family members or friends.

The second broad theme, *responsibility towards the resulting child*, was evident in each woman's description of her disclosure experience. Disclosure decisions were contemplated with the child's welfare held prominently in the decision. Despite the overwhelming concern for the welfare of the child, the women's intent to disclose varied. Four women indicated they were planning on informing the child of their reproductive origin. Of the remaining women, three women were undecided and one woman stated she was not planning to inform her

offspring. When questioned directly about their plans to inform the child, the women's statements varied from, "There is no question that we will tell our child - absolutely to, "I don't know... I just don't know.

## Factors

Underlying the two broad themes were the women's reports of multiple interrelated factors that influenced their reasoning, and ultimately, their disclosure decisions. These factors, although intertwined, are presented in two major categories: the women's values and beliefs, and social and cultural influences.

**Values and beliefs—**Foremost for the women were the values and beliefs associated with the right to know and the duty to protect. The belief that an individual had a moral right to the conceptual information was reported by the women as a reason or justification for disclosing. The values and beliefs the women held regarding their duty to protect justified both the women's choice for disclosure or non-disclosure.

**Right to know—**When the women reported that they told or planned to tell the nature of the conception to others, including their offspring, they often believed that the individual had a right to know about the use of donor oocytes. While the resulting child was the individual most often referred to as having a right to know, other individuals such as family members and health care professionals were also perceived as having this right. None of the women participants in this study described friends or other non-family members as having a right to know.

**Right of the child:** The right of the child to know and the benefit of knowing about their conception were described by both the women planning to disclose and those undecided about disclosure. For example, one woman, undecided about informing her twins, stated, "So, I have to really think in life how this information will be important to them ... I know it's important for health reasons but if you sign something that says you cannot contact the donor later, what's the point of the child knowing? Another undecided woman surmised, "But I don't know if it would be important to let them [twins] know. I don't know. I don't know...the benefit. Moreover, one woman who plans to inform her child stated, "We would definitely share that [the use of donor oocytes] because if there was a medical problem or just for future reasons I think the child should know about the history and things like that".

**Right of family members:** All of the women, regardless of their decision to inform their offspring, viewed certain family members as having a right to know about their method of conception. In addition to their partner, all of the women informed their own mother and father, if living. As one woman stated, "I feel I can't withhold the information, so I think when my mother asked a little bit more; I felt I had to [disclose the use of oocyte donation]. For some women, the right to know extended to other close family members as seen in this example: "There are some people that I think you need to tell like my sister. She's not happy but she needs these months to acclimate and accept.

**Right of health care professionals:** Some women expressed the right of health care professionals, such as their obstetrician, to know of their conceptual history. Although not all of the women voiced this belief, the women greater than 39 years of age stated they had told their obstetrician or obstetrical nurse about their use of donor oocytes when questions about amniocentesis or chromosomal abnormalities were addressed during the obstetric interview. As one 46-year-old women stated matter-of-factly, "For me in my position getting a donor egg, you have to make sure that certain people [obstetrician] know. This sentiment was not expressed by the younger women in the study.

**Duty to protect—**The women contemplated aspects of protecting the child, others, and at times themselves from harm. The values and beliefs they placed on aspects of their duty to protect influenced both the woman's choice for disclosure or non-disclosure.

**Protecting existing relationships and identities:** The women expressed concern that disclosing the nature of the conception had the potential to cause, or would cause, discordance in relationships and identities within the family. Concerns about maternal identity were reported by several women, as demonstrated in the following statement from one woman, who is planning on informing her donor oocyte child, "You know the only thing that struck me recently is when you have to tell these children how they were conceived, how they will react, will they still consider you their mother and all those kind of things. So I guess that it was just starting to make me feel a little insecure at that point - what's that going to be like?

Maternal insecurity was not the only self concern among the women. Informing other individuals of their use of donor oocytes or even having individuals aware of their infertility albeit indirectly, brought emotional pain and strife to several women. The duty they felt to protect themselves would, at times, be in conflict with the duty they felt to protect their child. These women described difficulty in disclosing their infertility history because it served as a reminder of the emotional pain and strife they experienced with infertility. As one woman who stated, "There is no question that we will tell our child. went on to report:

> I think in a way that egg donation could be, although we decided to be very open with people about the fact that this is what we did, but maybe at the time it made me think that I could be kind of normal. Like I'd be walking down the street and people would think, "Oh, she's pregnant." They wouldn't know anything about how I got to that place and nobody would even ever have to know. It's not like that I wanted to hide it even at that time or keep it a secret, but I just wouldn't have to explain it to anybody. Whereas when you adopt a baby, obviously you know. I guess I was just a little too worried about feeling like I had to explain myself to people and I thought well, this is perfect, I'll just be pregnant like everybody else and that would be fine.

Another woman, reflecting on her indecisiveness about informing her child stated, "Maybe it [disclosure] has to do with the fact that I have a hard time accepting my own infertility."

While the women voiced concern about protecting themselves from harm, the non-disclosing woman, who selected her sister as her donor, intensely described her concern for potential disruption of existing family relationships and identities should her child learn of the nature of its conception. Additionally, she voiced how she considered and honored her sister's request for non-disclosure to the child. The recipient woman stated:

> She [sister/donor] actually wants it [non-disclosure] more than I do. I mean it's mutual, but she says, "I'm the aunt, not the mom. I don't want her [oocyte donor child] coming to me in sixteen years saying 'Mom'." So no, she wants to be just the aunt and only known as the aunt. So we are all on the same page with that.

Then, the recipient woman later added, "But because [the oocyte donor] is somebody that she [oocyte donor child], it's a girl, will see on a regular basis and the fact that her cousins Kellie and Karen would not be her cousins, in fact they would be her sisters, I don't even want to get into that."

Protection of existing relationships extended into the women's selection of either a known or an anonymous oocyte donor and was interwoven with their overall disclosure decisions. For all of the seven women selecting an anonymous donor, their perception of having greater control over the conceptual information as well as the avoidance of complex relationship issues was important. For example, one anonymous recipient woman planning to inform her child

stated, “The idea of knowing the donor put too much relationship issues into play.” This sentiment was reported by the woman who selected a known donor and is not planning on telling her child. This woman reported: “If it was anonymous, I think we would maybe tell her” and then added, “If it was an anonymous donor, I wouldn’t have any problems with saying, ‘Mommy needed somehow something’ - along those lines.” The concern this woman voiced for protecting existing family relationships and identities was greater than other reported influences.

**Protecting from accidental disclosure:** All of the women verbalized awareness and concern for accidental disclosure to their child. They described, however, somewhat differing aspects of reasoning and behavior to mitigate this possibility. For the three women who were the most open with others, they planned to inform their child at a young age about the circumstances surrounding the conception as to prevent accidental disclosure. As one of these three women stated, “Because we’re going to be so open with family, I would never keep it from the child because I would have way too many people I would need to keep this thing a secret.”

In contrast, one woman also planning to inform her child reported that she had selectively told family members and when she did inform them about the nature of the conception, she did so with the request that the information remain private. Her statement, “I just asked them [her parents and her two sisters] to keep it within the family because at some point we’re going to have to tell the child. We’d rather tell them first than everybody know about it”, reflects a different approach for preventing future accidental disclosure.

The women who were undecided about telling their child and the non-disclosing woman also engaged in selective disclosure with other adults and typically requested the conceptual information remain private. In addition to controlling for accidental disclosure, the undecided women perceived their actions to be a mechanism for prolonging their indecisive period, thus allowing them the opportunity for telling or not telling their future child. The following excerpt, from one undecided woman, pregnant with twins, describes why she only informed her mother, father, and one close family member of her use of donor oocytes:

> The real reason is because I put it... for our child’s sake. We really don’t want to disclose the information [to other adults] ...[softly spoken]... that they’re donor eggs... More and more people find out and the child might be at risk to hear it and word travels and people talk without thinking sometimes. And if you are at social party or gathering, somebody might say something to me and our child is right there, or our children, I should say. So I think keeping it very private. Well, it’s our priority right now.

In another example, a woman, undecided about telling her children, summed up her reasoning in this way, “We may eventually tell them [children], but I’d rather not have everybody know and have the child not know. And then if something comes out someday - we don’t want that to happen.”

**Protection from shame and stigma:** Protecting the child from shame and stigma was a factor voiced by the women. Among the women who were planning to disclose the nature of the conception to their offspring, they described their intent to tell as based upon the belief that telling the child would avoid shame, secrecy, or lying, which they viewed as harmful to the child and the family. As one woman stated:

> I never ever want it [use of donor oocytes] to be something that the child ever thinks that I’m ashamed of or they should be ashamed of or it’s a secret or nobody knows because there are just connotations that it’s not good or it’s not... So there is no question [we will tell the child].

In contrast, another woman planning to inform her twins about their genetic origins at an early age, still feared social stigma and non-acceptance of her child by others - even young children. She stated:

> I have a fear that school children will call my babies, “test-tube babies.” If it becomes known then that you were the result of, “Your mommy’s not even your mommy!” ... school kids calling them names... there’re evil sometimes. So I’ve thought of that. That’s a fear.

Even though this particular woman planned on telling her twins, she reported the significance of continually protecting her children from stigma.

The women also reported concern about social stigma directed at them personally. When the women reported reluctance or preferred not to disclose their use of donor oocytes to others, the rationale for their nondisclosure differed among the younger and older women in the study. The women over the age of forty consistently described that their reason for non-disclosure was fear of other’s judgment and stigma of not only their use of donor oocytes, but also of their desire for pregnancy and childbearing at their mature age. As a 44-year-old recipient woman stated, “Most people have children in their twenties. Maybe they are a grandparent now. I haven’t told anybody at work [about the pregnancy], so many of them are younger.” Also notable from a 46-year-old woman describing her decision to not disclose her use of donor oocytes to other than a small number of individuals was, “Because then there is the other thing, ‘Well, you are too old to have a child’.”

Conversely, the younger women in the study did not report maternal age as a factor influencing their disclosure decisions; rather, the younger women reported that disclosure decisions were affected by their fear of stigma and the subsequent sense of embarrassment and abnormality they perceived about their diagnosis of infertility. As a 33-year-old woman stated, “You are ashamed, you are embarrassed, you don’t want anybody to know, it’s like you have this God-awful disease that nobody will come near you if they know you have it.”

**Social and cultural—**The women reported the significance of social and cultural influences on their disclosure decisions. The specific factors reported were social support, culture of the family, evolution of the social process, and personal testimonials.

**Social support:** The perception of social support in the form of others accepting or rejecting the use of donor oocytes influenced disclosure decisions. In instances when the women felt acceptance or support, disclosure occurred. On the other hand, when the women sensed rejection or judgment, they typically withheld information. This excerpt illustrates one woman’s dialogue with her close friend and the influence of social support:

> I told her [close friend] what my odds were with my eggs and then I mentioned there would be another scenario with donor eggs because we had gone through the IVF process. And there was a big pause at the other end of the phone. And I could tell even though because of her infertility experience, I felt there was a point where there was not really support in that [the use of donor oocytes] perspective. It was so foreign to her. She almost got blind sighted.

This particular recipient woman went on to state that she decided not to inform her close friend of her use of donor oocytes, but told her friend only of her use of in vitro fertilization.

Friends were not the only individuals subject to disclosure based upon their support. Family members were also evaluated for their support, and disclosure decisions were based upon the woman’s perception of their support. As this woman stated, “I can say my girlfriend is thrilled

and very supportive, but not my siblings. So, I don't know [voice diminishing] I don't really want to share that much with them."

**Culture of the family:** The culture of the family itself influenced the women's disclosure decisions. For example, women who voiced ease with telling other family members made statements such as, "My family has always been real open and we've talked about things." In contrast, another woman, who was very reluctant to tell family members about her use of donor oocytes, reported how her family's heritage is honored and there is a strong social preference for maintaining the existing culture and ethnicity of family members. These family values concerned her deeply and she feared telling her family about the nature of her twins' conception. In particular, she feared her family's comparisons of physical features between her children and the genetic family. She stated:

> It's a continuum. There are phases. I'm now thinking of the outcome, what are the children going to look like, whose characteristics are they going to have, behaviorally and physically? And how do I bridge that ...especially ethnic background, when lineage is the big thing, with the aunts and uncles saying, "Oh, he looks like the grandfather" and, "This child has the grandmother's characteristics - no it's got the mother's." And it goes back and forth. That is something I'll need to manage and know how to buffer and respond.

**Evolution of the social process:** Two women reported that their decision to inform others and their resulting child was not strictly a conscious decision but rather an evolution of the social process they went through during their infertility. One recipient woman described her decision to inform other individuals about her use of donor oocytes as follows:

> I would say [for] our close friends, they knew where we were at all the way along the line, so the idea of suddenly not talking about it would seem [pauses] false. So they knew every step we were going through mainly because they had experienced it themselves. So, the idea of when we got to an egg donor to suddenly not talk about it and to let perceptions be as they might be felt disingenuous to us. And certainly with our family that felt that way. So because of the fact that they had been there all along, I guess that helped us be that much more open about it... But I don't know if it was so much a conscious decision as it was just an evolution of the process we were going through.

When questioned specifically about informing the child, this recipient woman reasoned, "I wouldn't want to be at the point where... I would be going to family members or friends who know something they have to keep secret." Thus, for this woman, her decision to inform the child was made after retrospection of what had already occurred.

**Personal testimonial:** Two women reported being influenced by a personal narrative from a trusted friend or family member in which a testimonial was given to guide disclosure decisions. In particular, one recipient woman reported how her adopted friend strongly advised her to be open with her child. In this instance, the adopted friend encouraged openness to avoid the emotional strife and turmoil she endured when her adoption was revealed to her accidentally. In explaining her decision to tell her child, the recipient woman stated,

> But it's no different [than adoption] because my best friend is adopted and it did slip that she was adopted before her mom and dad felt it was ready... Her mom sat her down and explained everything... but that made us think more that we would definitely share that [the oocyte donor history].

## Discussion

Disclosure decisions by pregnant, donor oocyte recipient women are formulated through a complex, multifactoral, and dynamic process. The two broad themes identified from the women's disclosure experience were the overwhelming responsibility to the resulting child and the women's attempts to gain control over disclosure about conception. The factors, as delineated above, represent aspects of the women's experience which they perceive as important or influential to their disclosure decisions. Moreover, these factors provide unique insight into pregnant recipient women's reasoning for or against disclosure.

A number of studies have examined factors which influence disclosure decisions. The findings from this study support the importance of donor oocyte recipient's values and beliefs on disclosure decisions. Prior research has demonstrated that the right of the child to know is significant among disclosing parents (10,18-19,28-29). Less evidence exists about the influence of specific social and cultural factors upon donor oocyte recipient women's choice of disclosure; albeit, other investigators have demonstrated the importance of several sociocultural factors among other groups of individuals contemplating disclosure decisions (30-32).

Recipient individuals selecting non-disclosure have reportedly placed more emphasis on protecting the child from stigma and voiced concern that there is no compelling reason to tell (18-19,28,33). Only one woman who participated in this study indicated she was not planning to tell her child. Her reasoning focused upon protecting the child and others from relationship and identity discordance. Furthermore, she honored the request of her sister, the oocyte donor, for anonymity to the child to protect normative relationships.

Despite several reports that undecided parents voice more concern over how and when to tell the child (18,28-29), the undecided women in this study did not express this concern as influencing their decision. Because the women were early in pregnancy, concerns about telling the child may not be as paramount as when the child is actually present in the woman's everyday environment. However, it should be acknowledged that the women who were undecided about informing their child emphasized their contemplation over the protection of and benefits to the child, such as the acceptance of the child by other family members, as influencing their decision to inform their offspring. Also notable, several of the women opting for disclosure to the child asked the investigator for appropriate information on how and when it would be best to inform the child. Thus, it is plausible that both undecided and disclosing parents may need more information about how and when to tell the child.

Although maternal age was not examined as a unique entity, analysis of the data revealed several disclosure differences among the younger and older women in the study. Previous research investigating disclosure decisions among parents who used oocyte donation, IVF or ICSI to conceive children reported the age of the parent was not associated with whether the child had been told about their method of conception (16,34). While theses studies conclude there is no difference in the patterns of disclosure based on a woman's age, this study described differences in the woman's *reasoning* such that younger women fear non-acceptance and stigma because of their diagnosis of infertility and older women fear non-acceptance and stigma because of their mature status during childbearing. These are important distinctions. Understanding the difference in how younger and older women reason and perceive threats, not only to disclosing the means of conception, but to other elements interrelated within the donor oocyte experience, is essential when deducing how these factors affect their disclosure decisions. Additionally, the women greater than 39 years-of-age were more likely to tell obstetrical professionals about their use of donor oocytes.

The selection of a known or an anonymous donor was, in-part, contemplated in relationship to disclosure. For the women selecting an anonymous donor, disclosure decisions were made without the involvement of the oocyte donor. In the case of the recipient selecting her sister as the donor, the oocyte donor's preference for disclosure was considered and honored by the recipient. This may reflect significant control of the disclosure decision by the known oocyte donor. While the oocyte donor's preference for disclosing has been suggested as a factor in disclosure decisions (5), the extent of control in this case by the donor is unknown and little research exists that could enhance understanding in this area. Most of the research has focused on disclosure patterns based on donor type selected (12,14,16). The differing experiences of known and anonymous donor oocyte recipients and how choice of donor type impacts disclosure is unclear and warrants further investigation.

The results presented here should be interpreted with the understanding that all of the recipient women underwent a psychological counseling session for couples contemplating the use of donor oocytes at the recruiting infertility center. The center and the psychologists and other health care professionals are affiliated with the American Society for Reproductive Medicine, which supports disclosure to offspring (35). The extent to which the psychological counseling session influenced the women's disclosure decisions is unknown. While all of the women in this study reported the counseling session beneficial, several of the women openly questioned the disclosure recommendations made by mental health professionals. As one undecided woman stated, "I don't know if psychologists are always right."

Other limitations of the study were the self-selective nature in which the women chose to participate, and the small sample inherent in qualitative research. The results should be interpreted with caution as only one woman indicated she was not planning to inform her child. This, along with the small sample size may not have adequately captured other factors that influence disclosure decisions. Further research should include a larger, more diverse number of women, including men, who have also been significant in determining disclosure in other similar studies (17-18,28). Also, the investigation did not capture disclosure decisions made by the women prior to pregnancy, nor did it address possible changes in the women's disclosure patterns made as a direct result of the pregnancy or over time. A longitudinal study examining the influence of pregnancy on disclosure would be beneficial to both researchers and clinicians.

Nevertheless, the findings provide a detailed description of the disclosure experience of pregnant, donor oocyte recipient women and illustrate the factors which influenced their decision, from their perspective. Health care professionals can use the dense and factual account, generated from this phenomenological study, to increase understanding of women's disclosure decisions. Specifically, clinicians can improve patient assessment, communication, and anticipate concerns through increased awareness of the importance and influence of the patient's values and beliefs and social and cultural environment on disclosure decisions (36).

Noteworthy was the withdrawal of one eligible oocyte recipient woman after initially agreeing to participate in the study. Her actions provide evidence of speculation by other investigators that oocyte recipient women who prefer non-disclosure are more likely not to participate in research examining their disclosure experience (17). Although the percentage of women intending to inform the resulting child in this study (50%) is comparable to the 56% reported by Hahn and Craft-Rosenberg (18) and the 52% by Greenfeld and colleagues in their sample of anonymous oocyte donation in the United States (14), the actual percentage of women informing their child may be occurring less frequently than indicated.

## Conclusion

Understanding disclosure decisions from the pregnant, oocyte recipient women's perspective is important to health care professionals, as they have a unique roll in assisting women with

the disclosure process. Providing information and anticipatory guidance about disclosure issues is beneficial to recipient women and their children. Health care professionals can assist women with their disclosure decisions through awareness of the factors that women consider important. Knowledge of the woman's values and beliefs and her social and cultural environment can provide professionals with an understanding of the factors which will influence individual disclosure decisions.

Additionally, this study identified several differences between younger and older oocyte recipient women's disclosure experience and how they approach disclosure decisions. Likewise, the disclosure experience between women who selected an anonymous donor and the woman who choose her sister as her oocyte donor differed. Future research is needed to explore these differences and also to gain further understanding into the complex nature of formulating disclosure decisions, and what factors influence these decisions.

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**Table I**

INTERVIEW GUIDE

| |
|---|
| **First Interview** |
| 1. What are your thoughts about informing family members and/or friends that you have used a donated egg to become pregnant?<br>2. Have you told any other individuals about your use of a donated egg for pregnancy? If so, tell me about how you informed them and what their response was.<br>3. What factors did you take into consideration when you made the decision to inform others?<br>4. Are there individuals that you decided not to inform about your use of a donated egg? If so, can you explain how you made this decision?<br>5. Are you planning on informing the child that you are pregnant with about their biological make-up or family heritage? Tell me about your reasoning for this. |
| **Second Interview** |
| 1. Would you like to add any other information about your thoughts on informing other individuals, including the resulting child about your using donor eggs to have a baby?<br>2. Last time we talked you mentioned ... [question individualized to specificdisclosure content from 1st interview with woman]. Can you explain that some more? |