

## *Pregnant, Donor Oocyte Recipient Women Describe Their Lived Experience of Establishing the “Family Lexicon”*

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**Objective:** To describe the lived experience of pregnant women who used donor oocytes for conception.

**Design:** Qualitative, using a descriptive phenomenologic approach.

**Setting:** Interviews were completed at a location and setting selected by the participant. Of the 16 interviews, 13 were conducted at the participant's home, 1 was conducted at a private office, and 2 were conducted by telephone.

**Participants:** Eight women, between the ages of 33 and 46 years, were recruited at a large urban infertility center. The women were between 9 and 23 gestational weeks pregnant at the time of data collection. Each of the women participated in two open-ended, in-depth, audiotaped interviews and answered a demographic questionnaire.

**Results:** Four themes emerged from the women's description of their experience, which were (a) acknowledging the desire for motherhood, (b) accepting and coming to terms with donor oocytes as a way to achieve motherhood, (c) navigating an intense period of decision making, and (d) living with the lasting legacy of achieving motherhood through oocyte donation.

**Conclusion:** Clinical practice can be improved by incorporating recognition, support, and communication of the experience to women contemplating or undergoing donor oocyte treatment. *JOGNN*, 36, 161-167; 2007. DOI: 10.1111/J.1552-6909.2007.00128.x

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Over the past two decades, worldwide use of in vitro fertilization (IVF) has enabled many individuals

to establish conception, experience pregnancy, and achieve parenthood. Prevalence and success rates continue to climb in this area with significant gains reported when donor oocytes are used during IVF. In 1995, the first year in which assisted reproductive data were collected in the United States, there were 3,352 fresh donor oocyte transfer cycles performed, with an overall success rate of 35% (Centers for Disease Control and Prevention [CDC], 1997). The most current CDC (2005) statistics report an increase in fresh donor oocyte transfer cycles to 8,970 in 2003, with a success rate of 50%. The tandem increase in oocyte transfer cycles and success rate equates in a remarkable 282% increase in the donor oocyte birth rate over an 8-year period.

Coupled with the exponential gains in donor oocyte birth rate are concerns at a national and international level for the personal and societal consequences that donor-assisted reproduction embodies (Isikoglu et al., 2006; President's Council on Bioethics, 2004; Schenker, 1997; van den Akker, 2006). Despite the vast psychological and social implications, a lack of research exists in this area, leaving nurses and other health care providers with little evidence from which to guide clinical practice.

Understanding recipient women's experience is critical because of the increasing demand for treatment and the multiple personal and societal consequences that donor-assisted reproduction embodies.

Several investigators have examined behavioral components among donor oocyte recipient women; however, they have typically relied on questionnaire or survey data (Ahuja, Mostyn, & Simons, 1997; Applegarth et al., 1995; Greenfeld & Klock, 2004; Kirkland et al., 1992; Klock & Greenfeld, 2004; Lindheim, Kavic, & Sauer, 2000; Pettee & Weckstein, 1993) or have collected data during psychological counseling or screening sessions (Baetens, Devroey, Camus, Van Steirteghem, & Ponjaert-Kristoffersen, 2000; Greenfeld, Greenfeld, Mazure, Keefe, & Olive, 1998). Although the findings from these studies have expanded knowledge about treatment decisions (Ahuja et al., 1997; Applegarth et al.; Pettee & Weckstein), selecting an oocyte donor (Ahuja et al.; Applegarth et al.; Baetens et al., 2000; Greenfeld et al., 1998; Lindheim et al., 2000; Pettee & Weckstein), and disclosure decisions (Applegarth et al.; Baetens et al.; Greenfeld & Klock; Greenfeld et al.; Klock & Greenfeld; Kirkland et al.), there may be other significant dimensions of the experience which are not understood nor reported.

Attempts to bridge this gap have resulted in two investigations (Hahn & Craft-Rosenberg, 2002; Murray & Golombok, 2003) which aimed to understand aspects of the donor oocyte recipient experience from a humanistic perspective. These two studies specifically focus on describing the recipient experience of choosing whether or not to disclose to others the use of donor oocytes. Even though the findings promote understanding of donor oocyte recipient women's experience, the investigators' focus on disclosure limits other dimensions of the experience from being captured. Therefore, the purpose of this study was to describe pregnant recipient women's overall experience of using donor oocytes for conception. Because the study generated a large amount of rich data, particular aspects of the women's experience, such as a description of the factors influencing the women's decision to disclose their use of donor oocytes, is reported elsewhere (Hershberger, Klock, & Barnes, in press).

## Methods

Based on the study's purpose, descriptive phenomenology was selected as the appropriate design to uncover the essence of the experience (Husserl, 1931/1962; Spiegelberg, 1975). This approach seeks to understand and describe the human experience of pregnant, donor oocyte recipient women by revealing universal aspects of the experience and personal variations within the experience.

### *Sample and Setting*

Institutional review board approval was obtained and participants were recruited at a large metropolitan infertility center. Interested participants established contact with the investigator who asked the women to participate in two in-depth, audiotaped, open-ended interviews and to complete a

demographic questionnaire. Nine women expressed interest in participating and arrangements were made with the investigator to conduct the first interview at a location and setting selected by the participant. Noteworthy was one eligible woman who later called the investigator prior to the first interview and stated that she no longer wanted to participate in the study. Her reason for withdrawing was because she viewed participation as a potential mechanism for future accidental disclosure to her child, who she was not planning to inform about the conceptual origin.

The remaining eight eligible women completed all aspects of data collection and constitute the purposive sample for this study. The women, who were between the ages of 33 and 46 years, were all married, Caucasian, well educated, and held professional full-time employment positions. The majority of women (75%) were in their first marriage and the two remaining women had been married once previously. Most of the women (87.5%) and their spouses were child-free; however, one woman reported having stepchildren.

The women admitted to undergoing a wide variety of infertility treatments prior to donor oocyte treatment, ranging from ovulation indicators to IVF cycles using their own oocytes. Two women established pregnancy with their own oocytes during treatment; however, the pregnancies ended in first trimester miscarriage.

All of the women used the sperm of their spouse to establish conception. Seven of the women conceived on the first donor oocyte treatment cycle, and one woman underwent a second cycle using a previously cryopreserved donor oocyte embryo. The women were between 9 and 23 gestational weeks pregnant at the time of data collection. Five women were experiencing twin gestations and the three remaining women had singleton pregnancies.

### *Data Collection and Analysis*

A total of sixteen in-depth, audiotaped interviews were completed. Of these interviews, 13 were conducted at the participant's home, 1 was conducted at a private office, and 2 were conducted by telephone.

The first interview began with a broad open-ended introductory question specific to the purpose of the study which was, "What has it been like for you to be a recipient of a donated egg?" This format allowed the participant to describe the experience from their perspective and has been successful in other investigations on sensitive topics (Cowles, 1988; Sorrell & Redmond, 1995). The introductory question and others formulated the interview guide, which was generated from issues identified in the investigator's clinical practice, a systematic and extensive review of the literature (Hershberger, 2004), and consultation from both methodological and clinical experts. Attentive listening and probes were also used to assist participants to talk freely about their experience (Spiegelberg, 1975).

The second interview was designed for each individual participant to allow for expansion and clarification of any

information described in the first interview. The second interview began with the statement, "Is there anything that you have thought about since our first meeting that you wanted to discuss or clarify?" Then, questions that allowed for clarification were asked. In addition, a second interview is recommended when interviewing participants about sensitive topics (Cowles, 1988; Kavanaugh & Ayres, 1998).

The initial interviews ranged in length from 58 to 108 minutes and the second interviews ranged from 15 to 52 minutes in length. The interval between the participant's first and second interview varied from 2 to 3 weeks. Once each interview was obtained, the audiotaped recording was transcribed verbatim and checked for accuracy. Each woman received a \$25.00 honorarium in appreciation of her participation at the conclusion of the first interview.

The investigator kept field notes and a methodological and reflexive journal. Field notes pertaining to the interview environment, participant observations, and both the participant's and interviewer's reactions to the interview were recorded. The methodological and reflexive journal consisted of the interviewer's preconceived beliefs and ideas about the donor oocyte experience, scheduling and logistic information, and methodological decisions.

The collection of data followed a modified approach to Colaizzi's (1978) steps for phenomenology. Data management included development of eight case summaries. Each of the eight case summaries provided a succinct but comprehensive record of each participant's experience and contained information from the participant's interview transcripts, demographic data form, and the investigator's field notes and journal. Once all of the data were compiled, each of the interview transcripts and case summaries were reread to allow for familiarization and immersion with the data. Significant statements about the women's experiences were identified, and codes were developed. The codes served as a basis for identifying the significant dimensions of the women's collective experience and discerning personal variations within the experience. Emerging from the codes, were four major themes. After the themes were identified, the case summaries were again reviewed to ensure the themes remained true to the context of the experience. To enhance credibility (Beck, 1994) and consistency with Colaizzi's steps, all of the participants were contacted and asked to validate the themes and provide feedback. Their responses verified the themes and refined the description of the experience.

## Results

Four major themes emerged from the women's descriptions and constitute the essence of the experience. The major themes are (a) acknowledging the desire for motherhood, (b) accepting and coming to terms with donor oocytes as a way to achieve motherhood, (c) navigating an intense

period of decision making, and (d) living with the lasting legacy of achieving motherhood through oocyte donation.

### *Acknowledging the Desire for Motherhood*

The women described varying life experiences prior to their diagnosis of infertility. Constant among the women was their desire for motherhood even though the pathway taken in their lives toward motherhood was diverse. Several women reported a desire for motherhood deeply rooted in their life history, but they placed a value on motherhood in the context of marriage. Prior to their current relationship, these women were either unable or unwilling to identify a suitable spouse and therefore expressed a previous feeling of "giving up" on their desire for motherhood. Notable among some of these women was their consideration of single motherhood earlier in their lives. Although the women considered single motherhood, they described reluctance on their part to proceed toward motherhood without a legal partner. Their reasons for avoiding single motherhood varied from a perception that single motherhood was an activity beyond what they were capable of managing, as described in this woman's statement, "I thought, okay, I'm crazy if I think I can do that," and in another woman's expression of selflessness:

I don't really think it's fair. I think children need two parents. And often times parents get divorced and a single mother or a single father raises the child on their own. But there always to me is the intention that there are two parents building a strong structure for a child in the family. I thought that was selfish for me just to have a child [on my own].

Not all of the women described difficulty in identifying a suitable spouse. Some women made a conscious decision to remain childless in their adult life and later reconsidered this decision. One woman, married for over 10 years, described the couple's initial desire to establish careers. She explains, "We've been very career motivated and part of the reason why we're later parents is because of those priorities all the time." Yet another experience by a 33-year-old woman did not involve difficulty in identifying a spouse or other life priorities, rather she was unable to conceive despite attempts to establish pregnancy shortly after her marriage.

The women described various reasons as to why they wanted to become mothers. For some women, the desire was with them throughout their lives. These women described feelings such as "I just really wanted to be a mother" and "It is one of those things that I just always kind of assumed I'd be." Other women described a desire for motherhood that materialized during their adult lives. For example, several women voiced a desire to give back to society through motherhood. One woman explicitly stated, "We have a lot to offer. We have a lot to give. And to me it seems selfish not to want to build a family around that

and to just be concentrating on ourselves.” Conversely, one woman described her desire for motherhood was, in part, because it would enhance her own life. This woman purported, “I should not deny myself a great experience.” The women also expressed a need to establish a sense of purpose in their lives on a personal or intimate level. Several women reported a wish to provide their husband with a child. Comments such as “He’s a wonderful person” and “He will be such a great father—he is such a great person” were said with such loving care by the women that they were brought to tears during these statements.

### *Accepting and Coming to Terms With Donor Oocytes as a Way to Achieve Motherhood*

Each of the women described their realization of the limits of their fertility. Their descriptions of this experience ranged from calm acceptance to shock and disbelief. The women who were calm when describing their infertility stated how they grappled with their fertility prior to entering into treatment. One woman described her sentiments in this way: “We got married when we were older so going into it I kind of knew that once you hit forty your chances decrease dramatically. I mean it’s sad, but I was realistic about it too.”

For other recipient women, the loss of fertility was traumatic for them. When these women were presented with the option of using donor oocytes, they vividly described tumultuous experiences. One woman distinctly recalled, “He [her physician] just said, ‘Have you ever thought of donor eggs?’ And my first response was, ‘No way. No.’ I said, ‘No, not me!’” Upon hearing, her physician recommend donor oocyte treatment, another woman poignantly recalled, “The first time I had actually heard those words [donor eggs] I was very, very upset; very, I mean crying. It is probably almost worse than a death in the family. It was for me.”

**F**or some women, acknowledging the loss of fertility and undergoing donor oocyte treatment was worse than experiencing a death in the family.

As the women contemplated the use of donor oocytes, they described an awareness that their values were changing. One woman who reported her first response to using a donor oocyte was, “No, I don’t think so, it’s not for me” confessed, “As your options dwindle you find yourself re-evaluating previously held beliefs and thoughts.” This woman went on to state, “Don’t discount it [using donor oocytes] just because it sounds weird. Just because it’s something that you think that you won’t do—doesn’t

mean that you really won’t do it.” Another woman stated, “I became open to things that I never thought I would be open to in a period of a year.”

All of the women voiced how the advantages of using donor oocytes become apparent to them over time. The opportunity to experience pregnancy itself, to feel “normal” again, and to nurture and establish a bond with the child during the prenatal period was appealing to them. Providing their spouse with a genetically linked child was also significant as was reducing the chance of chromosomal abnormalities in their offspring among women 39 years or older. The significant disadvantage voiced and mourned by the women was the loss of their own genetic lineage.

### *Navigating an Intense Period of Decision Making*

Once the women accepted the use of donor oocytes, a period of intense decision making permeated their experience. First, the women selected either an anonymous or known oocyte donor. The women who selected an anonymous donor had the additional task of choosing the donor from among a composite of women. These potential oocyte donors were women who were recruited at an agency affiliated with the infertility center that specializes in identifying and obtaining oocyte donors. Then, the women described their experience of determining the disposition of cryopreserved embryos.

Even though seven women selected an anonymous oocyte donor, all of the women considered using a known donor. Some women reported that they were unable to identify an individual known to them who was capable of serving as an oocyte donor. In contrast, two women had close friends offer to donate their oocytes and two women had their biological sisters offer to donate. Except for one individual, the women declined to use known donors. For these women, future relationship concerns were the essential reason for not selecting a donor known to them. In contrast, the woman who selected her sister as her oocyte donor described why she chose her sister:

It was about family, and it was about, regardless of whose baby this is, I know who the grandparents are, I know who its aunt is, I know where it comes from, I know its background, I know she [the donor sister] was healthy while she was doing the medication and stuff.

The seven women who selected an anonymous donor described the additional task of choosing the donor from several individual profiles obtained from the donor oocyte agency. These profiles included information about the potential oocyte donor’s medical and obstetrical history, physical characteristics, and personality traits. The range of profiles reviewed by the recipient women was between 3 and 12; however, most of the women selected an anonymous oocyte donor from the initial three profiles presented to them. Regardless of the number of profiles reviewed,



the women described the selection of the donor as “sur-real” and “It was very strange actually. It really was kind of an odd process.”

The experience of deciding about the disposition of cryopreserved embryos was described by the women who had a combined total of 71 remaining embryos. Each individual woman had between 2 and 18 frozen embryos following the initial donor oocyte transfer.<sup>1</sup> Four of the women had formulated their disposition decisions at the time of the interviews and the remaining women were undecided. For the women who had reached a decision, multiple disposition options were described. For example, one woman with nine frozen embryos reported she plans to use two of the frozen embryos herself, for establishing a future pregnancy, and then plans to donate the seven remaining embryos to another infertile couple. Another disposition choice voiced by the women was to donate their embryos to research. The undecided women had formulated preferences for their frozen embryos but were unable to reach an absolute decision until they experienced life in the future. As one woman explained, “We’re not at that point. There may be an additional transfer [attempt at pregnancy]. I don’t know. I think we’ll have to kind of cross that bridge when we come to it.” This fluid state of decision making among the undecided women often included descriptions of religious beliefs and altruism.

### *Living With the Lasting Legacy of Achieving Motherhood Through Oocyte Donation*

Essential to the experience were thoughts and concerns for the future. These included worry about future contact and involvement with the oocyte donor, the importance of and access to evolving genetic information, and the effect of advanced maternal age on motherhood.

Awareness that the oocyte donor was now part of the “family lexicon” concerned the women. For example, the woman who selected her sister as her oocyte donor expressed concern about the future and the complexities involved within families when using a known oocyte donor.

And all along I thought, well, as I’m raising this child I can’t be yelling at this child in front of her because she’s going to think, “You can’t be mean.” Not that I would

be, but she’s going to question how I’m raising *her* child [italics added].

The anonymous oocyte recipient women also described concern about future association with the oocyte donor. Comments such as “We have this unknown third party that’s rather mysterious that’s involved in our life” and “Maybe we would meet [the oocyte donor]. That’s kind of a big unknown and scary thing, an out-there thing” typify the women’s focus on potential future contact with the donor.

The concern about raising a child, whose evolving genetic information would remain unknown to them, was prominent among anonymous recipients. As one woman stated:

Since these donors are under 28 years old, hell, under 28 years old I didn’t know I had endometriosis; I wouldn’t have known my mother had heart issues and my Dad had diabetes. You don’t know what the genetic background is, and they might not know. And so you don’t know what types of things they [her twins] could be facing in their future.

The women of advanced maternal age described their concern of the effect of their age on motherhood. When these women spoke about the future, their statements were made with intense emotion. As a 46-year-old woman stated, “But the biggest question was how do you feel about perhaps dying and not being there? That to me is the biggest issue [pauses]. I just plan to be very healthy.” These women voiced awareness of the consequences of establishing pregnancy at an advanced maternal age; yet, it was not something they fully accepted or even understood. It was as if their concerns about age stayed with them and was ever present: “I kept asking the agency and the nurses, ‘Am I too old? Am I too old?’ That was like my number one thing—am I too old? I think I’m too old.”

## **Discussion and Implications**

These findings illustrate the lived experience of pregnant, recipient women following donor oocyte transfer. Of significance was the description of the various priorities the women had in their lives. A constant priority among the women in this study was the prerequisite of marriage prior to childbearing. This priority demonstrates an interesting paradox among oocyte recipient women. Although some women openly choose single motherhood (Siegel, 1998), recipient women voiced a preference for motherhood within the context of marriage. This emphasis on a traditional social value can be viewed in direct conflict to the use of donor oocytes, one of the most advanced, and hence controversial, reproductive technologies available worldwide. Thus, it may explain why the women described changing beliefs and for some, turmoil, when they were deliberating the use of donor oocytes.

<sup>1</sup> Supernumerary embryos are a result of IVF procedures whereby the number of developing embryos exceeds the number of embryos for which the physician and patient have agreed to transfer to the uterus in a cycle. For additional information, see the guidelines issued by the Practice Committee of the Society for Assisted Reproductive Technology and the Practice Committee of the American Society for Reproductive Medicine (2006) on the recommended number of embryos to transfer.

An important finding was the relationship concerns described by the women for both selecting and rejecting both types of donors, known or anonymous. This finding extends existing research that women's primary concern for selecting an anonymous donor were fears that a known donor would want to participate in parenting (Greenfeld & Klock, 2004). Even though the known oocyte recipient woman in this study voiced her concern about her sister's involvement with the child, the recipient's perception that using a biologically related donor would allow for a greater sense of family and knowledge of medical and genetic information superseded relationship concerns.

The significance of knowledge about the oocyte donor's evolving genetic information was not only important to the recipient of known donation but also an expressed concern among the anonymous oocyte recipients in this study and in another investigation (Petee & Weckstein, 1993). In view of the current worldwide milieu toward informing donor oocyte recipient children of their conceptual nature (Department of Health, 2004; Ethics Committee of the American Society for Reproductive Medicine, 2004) and the emphasis placed on genetic information in health care, nurses should encourage and participate in the development of clinical frameworks that would allow for the transfer of evolving genetic information between recipient, offspring, and donor.

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With nearly 400,000 frozen embryos in the United States in 2002 (Hoffman et al., 2003), the women's decision making about the disposition of cryopreserved embryos offers insight into the complexities surrounding third-party reproduction. Noteworthy was that dimensions of the experience included descriptions of the interplay of religious beliefs and altruism. Although the indecisiveness in terms of embryo disposition described by some of the women may be attributed to the unknown outcome of their pregnancies, another qualitative analysis of donor oocyte recipient women and their husbands found 72% of them were undecided despite having cryopreserved embryos for 1 to 11 years duration (Nachtigall, Becker, Friese, Butler, & MacDougall, 2005).

Essential to the women's experience were concerns about the future, specifically the impact of motherhood at

an advanced maternal age. With an increasing number of women 39 years and older using donor oocyte treatment throughout the world (CDC, 2005; Rabinerson et al., 2006; Söderström-Anttila, 2001), the findings suggest that these women would welcome discussion, education, and anticipatory guidance on this topic.

Since the composition of the sample in this study consisted of a homogeneous group of married, White, well-educated, professional women, future research is needed to explore the similarities and differences among women of differing cultures, religions, or socioeconomic status. More in-depth research is also needed to describe the experience of subpopulations of women who differed from this sample based on their decisions within the experience, such as women who select a donor known to them.

In summary, nurses and other health care providers can use the findings presented here to enhance clinical practice and stimulate future research. Incorporating recognition, education, anticipatory guidance, and support of the experience to other women who are contemplating or undergoing donor oocyte treatment would improve the standard of care (Kearney, 2001). Nurses need to develop clinical frameworks to facilitate communication of evolving genetic information among women recipients of oocyte donation and their donors. Future research examining the donor oocyte recipient experience among diverse groups of women and specific aspects of the experience would enhance understanding.

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