

Parents' conceptualization of their frozen embryos complicates the disposition decision

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Objective: To ascertain what couples think about their embryos and how they approach making a decision about disposition in light of the fact that the disposition of unused frozen embryos has significant implications for medical research and embryo donation.

Design: Ethnographic qualitative interview study.

Setting: Academic research environment.

Patient(s): Fifty-eight couples who had conceived using a donor oocyte and had at least one frozen embryo in storage.

Main Outcome Measure(s): Tape-recorded interviews with 58 wives and 37 husbands were transcribed and analyzed for emergent themes.

Result(s): With an average of 7.1 embryos per couple, after an average of 4.2 years of storage, 72% of couples with frozen embryos had not reached a disposition decision. Most couples had not anticipated or appreciated the consequences of having surplus embryos. Parents variously conceptualized frozen embryos as biologic tissue, living entities, "virtual" children having interests that must be considered and protected, siblings of their living children, genetic or psychological "insurance policies," and symbolic reminders of their past infertility.

Conclusion(s): The disposition decision is not only a significant and frequently unresolved issue for couples with stored frozen embryos, but their deeply personal conceptualizations of their embryos contributes to their ambivalence, uncertainty, and difficulty in reaching a decision. (*Fertil Steril*® 2005;84:431–4. ©2005 by American Society for Reproductive Medicine.)

Key Words: Frozen embryos, embryo donation, embryo disposition

The expansion in the annual number of IVF procedures performed in the United States from 2,389 in 1985 to over 77,000 in 2001 (1) has had an unforeseen consequence: the accumulation and storage of an estimated 400,000 "surplus" frozen embryos (2). As a result, thousands of couples are faced with the dilemma of what to do with their frozen embryos, that is, the "disposition decision." The couples' decision is inherently complicated by the variety and disparity of the potential embryo uses and outcomes: they can be used by the couple in further attempts to conceive; they can be "donated" to other infertile couples who wish to have a child; they can be used in medical research; they can be destroyed; they can be disposed of by intentionally transferring them at a time that precludes implantation; or they can be stored indefinitely. In addition to the personal challenge of the disposition decision, what couples decide to do with their frozen embryos has a direct impact on two areas of public health policy that are currently embroiled in uncer-

tainty and controversy, specifically, the use of frozen embryos for stem cell research and their donation to other infertile couples.

Klock et al.'s (3) recent report that 82% of couples who had initially indicated a desire to donate their embryos to another infertile couple and 88% of couples who had originally chosen to donate their embryos to research changed their minds indicates that couples address this issue with considerable uncertainty. Yet other than McMahon et al.'s (4) interviews with mothers who conceived with IVF in Australia, there has been little research on how people who have stored frozen embryos actually think about them or how they go about coming to a disposition decision. Without more comprehensive information about the circumstances in which couples might be willing to donate their unused frozen embryos to research or other infertile couples, it is impossible to estimate the impact that embryo donation might have on the future of stem cell research or infertility treatment.

During an ongoing qualitative research study interviewing couples who conceived with IVF and donor oocytes, we were struck that several couples commented that contemplating the fate of their embryos was harder than their decision to go forward with the donor oocyte procedure itself. Noting that most of these interviewed couples had not yet taken any action toward disposition, we began to sys-

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tematically collect interview data about embryo disposition from parents who had stored frozen embryos. A review of the complex, nuanced responses found in these interview transcripts is the basis for this report and suggests that the disposition decision is an involved and dynamic process.

MATERIALS AND METHODS

The findings of this article are derived from a subset of the interview data collected as part of ongoing ethnographic qualitative research on how parents of children conceived through the use of donor sperm or donor oocytes make their decision about whether or not to tell their children of the true biological nature of their conception. Heterosexual married couples who had conceived at least one currently living child through either donor insemination or a donor oocyte were recruited from 10 assisted reproductive technology practices located in four counties in northern California. Prospective participants were contacted by mail by their medical provider. The mailing included a brief description of the study and a stamped return postcard and envelope addressed to the investigators indicating willingness to be contacted by telephone to receive additional information about the research. Those who returned affirmative responses were contacted by an investigator to further explain the study and to schedule an interview.

A 53-question semistructured and open-ended in-depth interview with the husband and wife together was followed by a 26-question interview with each partner separately approximately 3 months later. The interviews, which were tape recorded and transcribed verbatim, generally last from 1–2 hours. When interviews began in early 2002, we noted that many respondents who had used a donor oocyte to conceive volunteered that they had unresolved issues about what to do with their unused frozen embryos.

In response to these concerns, we began to systematically collect additional data on the subject of frozen embryos by adding the following open-ended questions about the embryo disposition decision to the interviews of those couples who had conceived with donor oocytes:

1. Did you have any frozen embryos left over?
2. (If yes) Have you decided what to do with them?
3. When did you realize that making a disposition decision would be a question for you?
4. What decision have you made or what options are you considering?
5. What factors have influenced your decision/consideration on this subject?
6. How do you feel about your decision/consideration at this point in time?

The data were analyzed by examining the transcripts for respondents' views, descriptions, and expressions of what they considered meaningful. These responses were then broken down into discrete statements, sentences, phrases, or paragraphs that expressed an opinion, stance, feeling, or

TABLE 1	
Demographic composition of interviewed respondents.	
Characteristic	n
Gender (%)	
Women	58 (61%)
Men	37 (39%)
Mean age, years (range)	
Women	45.6 (35–59)
Men	46.9 (32–64)
Mean no. of frozen embryos (range)	7.1 (1–28)
Mean age of frozen embryos, years (range)	4.2 (1–11)
Ethnic background (%)	
Caucasian	96
Asian	3
Latino	1
Education (%)	
High school graduate	11
College graduate	36
Advanced degree	53
Religion (%)	
Protestant	39
Catholic	20
Jewish	13
None	28
Median household income (\$)	150,000

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concern. The investigators then met to develop consensus about categories of meaning, the relationships between categories, and the development of themes, while taking into account the range and variation in the data.

This study was approved by the Committee for Human Research at the University of California, San Francisco, and was approved and supported by the National Institutes of Health and Child Development.

RESULTS

Of a total of 588 study invitation letters posted to couples who had conceived using a donor egg, 80 couples were interviewed for a participation rate of 14%. Of the 80 couples who conceived using a donor oocyte, 58 had from one to 28 frozen embryos in storage. From these couples, all the wives and 37 husbands were interviewed. The demographics of these 58 couples (presented in Table 1) indicate that this sample is predominantly white, highly educated, and affluent.

Of the 58 couples with frozen embryos in storage at the time of the interviews, 42 (72%) had neither acted upon nor were in the process of acting upon a disposition decision. Of

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