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Parents' conceptualization of their frozen embryos complicates the disposition decision

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Abstract

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.

Keywords

Frozen embryos; embryo donation; embryo disposition

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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 uncertainty 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 systematically 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 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 the 16 who had come to a disposition decision and acted on it, seven couples donated their embryos to research, five couples had their embryos destroyed, two couples donated their embryos to another couple, and two couples used them in further attempts to conceive.

Analysis of the interview transcripts suggested two major interrelated findings: The first is that the disposition decision process roughly follows four temporally sequential stages:

Stage1.

Reassurance—While undergoing IVF treatment, couples are reassured by having large numbers of surplus embryos.

Stage2.

Avoidance—Once their childbearing is completed, most couples spend little time thinking about their frozen embryos.

Stage3.

Confrontation—When couples actually begin to confront the disposition decision, their reaction is frequently one of discomfort and uncertainty. Several identifiable elements contribute to the difficulty of coming to a disposition decision.

Stage4.

Resolution—Those couples who were able to come to an agreement frequently expressed a profound sense of completeness and resolution.

The second major finding is that the factor that contributes most significantly to the difficulty of the disposition decision is the complex nature of the couples' conceptualization of their embryos.

We found that not only do virtually all couples recognize their embryos' potential for life, their conceptualizations incorporate a wide variety of deeply personal meanings that complicate their ability to reach a disposition decision. For example, while some couples thought of their embryos as little more than biologic material, some couples envisioned their embryos as living entities with the capacity to experience discomfort and even suffering and were thus unable to contemplate their destruction. Many thought of their embryos as “virtual” children that had interests that must be considered and protected; the thought that the welfare of these “children” might not be under their control was a major issue when couples considered donation to another infertile couple.

Furthermore, many parents not only thought of their embryos as independent potential children in their own right, but incorporated them into the family structure by referring to them as siblings of their living children. This view complicated the consideration of donating embryos as it gave rise to concerns about the possibility of their living child inadvertently meeting and starting a relationship with a child conceived from a donated embryo.

There were other elements of the parents' conceptualizations that complicated disposition decision making. For example, some couples considered the potential value of their frozen embryos as a kind of genetic or psychological insurance policy and considered the possibility that their embryos might provide some medical benefit to their living children at some future time. Others even discussed the possibility of having them as potential replacements for their living children should they be lost through illness or accident.

A final element complicating the disposition decision was that couples frequently conceptualized their frozen embryos as symbols of the infertility that had dominated their lives for so many years. For some couples, the embryo solution was to “use them up” by having more children, while for several women the existence of the stored embryos continued to fuel their desire for more children even when that longing was impractical for medical or personal reasons. For others, embryos were “unfinished business” that required having to directly confront the painful memories of their own struggles with infertility. This revisiting of the infertility experience sometimes led to a consideration of embryo donation out of empathy for other infertile couples, yet couples considered embryo donation as having a meaning that was uniquely different than either gamete donation or adoption.

DISCUSSION

The finding that 72% of the couples in this study had not come to a disposition decision is in congruence with previous observations indicating that the frozen embryo disposition decision is a significant and frequently unresolved issue in couples' lives in many countries. For example, in the United States, Klock et al. (3) found that 71% of couples who had embryos that had been frozen and stored for at least 3 years changed their preference after the initial

contact. Similarly, McMahon et al. (4) found that 70% of Australian women with surplus frozen embryos were unable to come to a disposition decision 5 years after their IVF birth.

Our findings suggest that the disposition decision can be seen as a dynamic process that temporally unfolds in stages that begin at the time of original embryo storage. One root cause of the ambivalence about the disposition decision is that couples are initially focused on the immediate goal of achieving a pregnancy while working their way through the complex intermediate steps and decisions required by the IVF technique and do not anticipate that having surplus embryos will present a challenge in the future. During this initial reassurance stage, the ability to store surplus embryos is viewed as a bonus because at this point the couples do not know how many attempts they will need to achieve their first (and subsequent) pregnancies. Yet once pregnancy had been successfully achieved and their childbearing completed, the second-stage reaction of most couples was characterized by avoidance of the issue, most commonly by just keeping the embryos frozen, often with the implied assumption that the decision could be postponed, perhaps indefinitely.

When couples finally entered the confrontation stage, often prompted by bills or reminders from the embryo storage facility, their initial reaction was frequently one of discomfort and uncertainty. Part of the distress for several couples was that they were not immediately comfortable with any of the disposition options. Yet the couples also felt the importance and weight of the decision and wanted to make a responsible and moral determination. Many couples felt isolated and expressed the desire to talk to other couples who were in the same position while commenting on the lack of support, information, and guidance about the disposition options and the decision-making process. Yet it bears emphasis that a quarter of interviewed couples were able to come to a united disposition decision for their frozen embryos and acted on it. Those that reached this final resolution stage frequently expressed a sense of satisfaction and completion.

The concept that surplus frozen embryos can be donated to medical research or other infertile couples is a relatively recent development. Despite earlier reports that couples were four times more likely to destroy their frozen embryos than donate them (5) and that only 3%–5% of cryopreserved embryos were available for donation (2,6,7), in 2002 the U.S. Department of Health and Human Services announced a \$900,000 program to increase the public's awareness of embryo donation (8) while the American Society for Reproductive Medicine issued guidelines for obtaining informed consent from patients who may wish to donate their embryos for medical research (9).

In 1995 Robertson (5) conjectured that two major determinants of a couples' willingness to donate their embryos would include their interpretation of "embryo status" and their ability to accept not having contact with their donated "genetic offspring". The findings presented in this current study strongly support Robertson's hypotheses and lead us to conclude that parents' deeply personal conceptualizations of their stored frozen embryos are a major factor in their ambivalence, uncertainty, and difficulty in reaching a disposition decision.

There are acknowledged limitations to this preliminary study. The most significant is that because this work arose from an examination of parents who had conceived through the use of donor gametes, the only frozen embryos under consideration in this study are those that resulted from the use of donor oocytes. In fact, the overwhelming majority of frozen embryos that exist in the United States were created as a result of IVF cycles in which the gametes were those of the husband and wife. Although McMahon et al.'s (4) report that most mothers with frozen embryos conceived through IVF in Australia expressed similar conceptualizations to those reported here, especially with respect to the embryo's potential for life and "relatedness" to their living children, it is possible that the wife's conceptualization of frozen embryos and

subsequent disposition decision may be influenced by whether the embryos were derived from her own genetic material or from that of a donor. For example, a couple could be more inclined to consider embryo donation if they themselves conceived a child using a donor, or, on the other hand, the donation of an embryo conceived with a donor could be complicated by the need to address the interests of the donor as well as the donating couple.

Because qualitative process studies are concerned with the thoughts, feelings, attitudes, actions, and experiences of the research participants, we believe that this interview methodology is well suited to the assessment of complex personal issues such as the disposition decision. At the same time we recognize that the thematic portrayal of experience is selective and is subject to change depending on the context and the temporal nature of experience (10). Although themes can be viewed as cultural resources that people draw on to make sense of events in their lives (11), those resources change with time and circumstance; that is, in subsequent interviews people may take up different topics that reflect more recent experiences.

The 2003 RAND study reported that almost 90% of frozen embryos are targeted for patient use (2), yet the findings presented here suggest that counseling at the time of cryo-preservation may not adequately address the emotional or practical implications of having surplus frozen embryos after childbearing has been successfully completed. Noting that many couples commented on a perceived lack of support, information, and guidance, we believe that further examination of the disposition decision is called for and plan to initiate such research in the near future. A more complete exploration of the disposition decision using a broader sample of potential embryo donors would not only inform medical and mental health professionals and assist in the development of educational and counseling protocols, but would give a measure of couples' response to the concept of embryo donation and address the issues that influence a couple's receptiveness to the use of embryos for medical research.

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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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