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What do patients want? Expectations and perceptions of IVF clinic information and support with respect to frozen embryo disposition

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Abstract

Objective—To describe frozen embryo-holders' expectations and perceptions of IVF clinic information, support, and storage fees and their relevance to embryo disposition decision-making.

Design—Qualitative interview study.

Setting—Three Northern California IVF practices.

Patients—One-hundred and six families (110 women and 74 men) with an average of 6 frozen embryos in storage for 5 years.

Interventions—Three in-depth interviews over one year.

Main Outcome Measures—Thematic analysis of interview transcripts.

Results—While embryo-holders expected that IVF clinics were under obligation to assist in the disposition decision and would be their main source of information, these expectations did not become manifest until years after embryo cryopreservation. Patients expressed a variety of preferences for the timing, format, and content of information and support ranging from detailed written information to counselor/advocates that could provide logistical guidance and/or psychological support. Embryo-holders perceived an insufficiently defined infrastructure to facilitate donation to other couples whereas donating to medical research was seen as less complicated and more likely to be encouraged and supported by physicians and clinics. Although increasing storage fees motivated disposition decision-making, they could be interpreted as coercive and/or not reflective of actual clinic costs.

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Conclusions—Frozen embryo-holding patients' expectations of information and support to assist them with disposition decision-making and embryo donation suggests that IVF clinics may benefit from a review of their frozen-embryo counseling, storage, and disposition policies and procedures.

Keywords

frozen embryos; embryo disposition; embryo donation; embryo storage; discarding embryos; Clinic; IVF; Information; Support

INTRODUCTION

An accumulating literature has described the frozen embryo disposition decision as often difficult with a majority of embryo-holders frequently unable to choose between further attempts at conception, continued storage, donation, or embryo destruction (1–17). Because of the intensely private nature of this choice (2), it is not surprising that investigations have identified a variety of personal contexts influencing the decision-making process (1–3,5,7, 10–13,18–20). In this paper we address an external context that has received relatively less attention, namely, frozen embryo-holders' expectations and perceptions of IVF clinic information, support, and storage fees and its relevance to disposition decision-making and implications for IVF clinic policies and procedures.

MATERIALS and METHODS

Participants were recruited from three large IVF practices in Northern California and the study protocol and consent form were approved by the Institutional Review Board of the University of California, San Francisco. Participants underwent three semi-structured interviews, each one to two hours long, at six-month intervals. Themes, ideas, and concepts that appeared in the interview transcripts were identified and code words defining and referencing these themes were developed. This report reflects an analysis of the interview data identified by the codes that referenced encounters and experiences at the clinic including relationships with the doctors and staff with respect to support, advice, and opinions sought or received (and their adequacy and utility in making disposition decisions) as well as communications from the IVF clinic referencing storage fees, consent forms, clinic policies and restrictions, and general or specific information on embryo disposition. Unbiased analysis was achieved via data collection, analysis, and inter-rater reliability checks by multiple investigators (21).

RESULTS

A total of 342 interviews were performed with 110 women and 74 men from 106 families with stored frozen embryos. The majority were Caucasian, employed, married, college educated, identified as a member of a religious group, and reported median incomes of over \$100,000. The median number of living children was two per family. The median number of stored embryos per family was six and the average number of years in storage was five years at the time of the final interview. The average annual cost of storage was approximately \$500. By the end of the study 26 (24%) of undecided families chose to deliberately store embryos indefinitely, 42 (39%) favored donation to science, 6 (6%) favored using embryos for further attempts as conception, 7 (7%) favored donation to others for family-building, and 3 (3%) favored embryo destruction. The remaining 22 families (21%) remained undecided at the final interview one year later see (Table 1). A detailed account of disposition decision-making experiences of these embryo holders has recently been published (2).

Our analysis suggests (a) the provision of information and support by the infertility clinic played an important role in the disposition decisions made by embryo-holders; (b) participants

expected that their physician/IVF clinic would be their main sources of information regarding frozen embryo disposition; (c) participants believed that clinics were under some obligation to assist in the disposition decision because the surplus embryos were generated as a result of the IVF procedure, and (d) embryo-holders voiced a wide range of expectations and preferences for the timing, nature, and specific content of information and support.

Participants looked directly to their clinics and physicians for skilled, informed, personal guidance because they had established a trusting relationship during the IVF process, and believed that physicians had greater access to relevant information. Yet many participants noted that communication with the clinic decreased drastically after they successfully conceived. Others remarked about perceived discrepancies between the amount of information they received in preparation for their IVF procedure and what they received concerning embryo disposition.

Participants were divided over having preference for detailed information about disposition decision options before initiating their IVF cycles or after their pregnancies had been established. While some perceived having to process additional information while they were intensely focused on achieving a pregnancy would have been “overwhelming,” others felt that having more information before they initiated their IVF cycles would have “laid the groundwork” for future decision-making. Of notable effect was the photograph of their embryos given to many participants prior to embryo transfer. Having this picture often led to an increased attachment to the embryos which complicated or inhibited later embryo decision-making. Yet most participants acknowledged that even if they had been more aware of potential challenges of frozen embryo decision-making earlier, achieving a pregnancy was their greatest priority at that time and few would have changed their course of action.

Participants voiced a variety of preferences for receiving information, support and counseling from their IVF clinic. Many embryo-holders wanted detailed written information, but some cited the impersonal nature and relative lack of “importance” or “impact” of pamphlets or other written material, and thought it would be helpful to have a follow-up educational seminar. Several would have liked the opportunity to participate in support groups with other embryo-holders while others envisioned trained, unbiased, “professional” counselors or advocates to provide guidance ranging “sorting through the options” to purely emotional support.

Participants’ recollections of the number and “quality,” “viability,” or “grade” of their embryos at the time they were frozen influenced their decision-making. Participants were particularly interested in (and often uncertain about) how long embryos could remain in storage and still be used for further attempts at conception. Embryo-holders who had few or “low grade” embryos questioned whether it would be worth the emotional and/or financial investment to attempt additional frozen embryo transfers. Participants who had conceived children with frozen cycles were more likely to see frozen embryos as viable.

Some participants remembered receiving information about embryo donation, while others did not and were confused as to whether this was truly an option. Most wanted to select specific criteria for recipients. Ultimately, some participants who initially expressed interest in embryo donation reported abandoning it in part because of the perceived lack of a defined, non-sectarian infrastructure to facilitate donation.

Many participants recalled receiving more information about options for donation to science than about other alternatives, and perceptions of implicit or explicit encouragement by the physician or clinic often played a crucial role in disposition decision-making. Participants solicited by their infertility providers with an option to donate to research often referenced their positive experiences and sense of trust established over the course of their clinical relationship and were not only more likely to donate to science, but, when possible, to donate to a clinic-

affiliated research project. Yet a few voiced concerns about the potential for communications to be coercive, or present a conflict of interest.

A perceived lack of information (from IVF clinics, research organizations, or elsewhere) was frequently associated with expressions of generalized fears about science which inhibited disposition decision-making overall and appeared to dissuade some embryo-holder's from donating to research. For example, participants voiced concerns about embryo misplacement, disposal, or use in the creation of chimeras, for eugenic purposes, or having embryos "grown into babies" for experimentation or a "black market." Although many participants expressed the desire for detailed information about research options, including the ability to choose the specific research project for scientific donation of their embryos, others remarked that they would not want to know "too much" about the actual physical procedures that would be applied to donated embryos, anticipating discomfort from knowing details. Some embryo-holders reported that too much medical or scientific terminology could be overwhelming and effectively halt decision-making.

While the vast majority of participants thought the act of discarding embryos was a "waste" of a "precious" resource, the perception that "low-quality" embryos would not be useful for other purposes made the idea of discarding acceptable for a few embryo-holders. Participants reported having very little information about the process of discarding and did not have a sense of what the procedure entailed. Some mentioned the possibility of having them discarded while present in the clinic or being able to take them from the clinic themselves.

Most participants reported that the only post-IVF communication they had with their clinic was correspondence related to storage fees. For those contemplating near-term attempts at conception the monetary costs associated with embryo storage were perceived as acceptable. For participants who viewed their embryos as an "insurance policy," the costs associated with embryo storage were considered acceptable when their children were young, but as their children aged, the storage costs were perceived as less satisfactory, particularly by the non-gestational partners. Those who were less committed to further attempts at conception reported being influenced to make a decision by actual or anticipated increases in storage fees. Participants were also less committed to bearing the costs of indefinite embryo storage when they felt that they were storing the embryos for use by recipients other than themselves. Some wondered if there was any point in continued storage if the embryos were no longer viable over time.

DISCUSSION

While an increasing body of literature has described the complex and nuanced personal contexts of frozen embryo disposition decision-making (1–3,5,7,10–13,18–20), in this paper we address the influence and relevance of an external embryo context, i.e., embryo-holders' expectations and perceptions of IVF clinic information, support, and storage fees. We found that embryo-holders perceived that their physicians and IVF clinics were under obligation to assist them in be disposition decision-making, and voiced a wide range of expectations and preferences for the timing, nature, and specific content of information and support.

While the question has been raised whether the informed consent process at the time of cryopreservation adequately prepares embryo-holders for the potential future challenges of embryo disposition (4,5,10,12,15,19,22), we found no unanimity of opinion about whether embryo-holders want more embryo disposition information at the time of cryopreservation (12,15,23) nor a significant indication that more information would have changed their cryopreservation decisions. While providing more disposition information at the time of cryopreservation should not be presumed to completely ameliorate later disposition-decision

challenges (2,4,12,15,24), it may serve the useful purpose of engaging embryo-holders in the disposition decision-making process sooner.

We found support for the observation that relatively few embryo-holders decide to donate their embryos to others despite expressions of altruism, reciprocity, and identification with other infertile people (5,10,11,19,24–26). While concerns about responsibility and kinship ambiguities have been well-explored (1,2,10,12,27), deficiencies at the information and support level were also dissuasive to potential embryo donors. The first of these is a lack of awareness of the option (28,29) and the second is a perceived lack of a clear mechanism for donation. Without direct support and guidance, embryo-holders faced not only the initial prospect of locating suitable recipients, lending support for “conditional donation” (19), but additional and uncertain subsequent financial, legal, religious, and medical burdens such as genetic and infectious disease testing screening required to qualify them as donors (2).

On the other hand, when compared to the option of donating embryos to others, our findings are consistent with recent observations that donation to science is an increasingly popular disposition option (6,7,13,15,30,31) and suggest personal and informational explanations for this dichotomy. At the personal level, donating to science allows for the expression of altruistic values, but obviates future obligations, responsibilities, or entanglements with recipients or potential offspring (1,2,12,30). The informational explanation is that participants not only reported receiving more information about donation to science than donation to others, but some cited direct contact with and encouragement from their physicians as influential in decision-making. Furthermore, a perceived lack of information (from the IVF clinics, the research organizations, or elsewhere) was frequently associated with expressions of distrust or fear (7,12,25) which appeared to dissuade some embryo-holders from donating to research. Yet some embryo-holders reported that too much medical or scientific terminology could be overwhelming and effectively halt decision-making (12,23).

While the vast majority of participants thought the act of discarding embryos was a “waste” of a “precious” resource, most participants lacked any real information about what the process actually entailed. In the absence of specific information, those who voiced distrust in science, scientists, physicians, or clinical quality control argued that discarding would prevent embryos from being misused or inadvertently or deliberately transferred to others (2,11,15). The observation that participants who had fewer or “low quality” embryos were more open to the idea of discarding them lends support to observations that clinicians not only have influence over embryo decision-making in general (12), but are instrumental in whether patients view their stored embryos as “viable” or “alive” (7).

We found that participants’ attitudes towards storage fees in general varied with their stage of decision-making and were most accepted when further attempts at conception were being considered. While some participants perceived that storage fees reflected actual clinic costs, others believed that clinics used storage fees to either encourage patients to make disposition decisions or to generate income. Some participants expressed dissatisfaction about increases in fees but felt that they had little recourse but to pay until they were ready to make a disposition decision or have their embryos discarded. However, most participants acknowledged that if there were no fees associated with storing embryos, they would have very little motivation to make a disposition decision and would instead keep the embryos in storage indefinitely.

From the IVF clinic’s perspective, maintaining large numbers of frozen embryos is an expensive and time-consuming task. While the American Society for Reproductive Medicine has described conditions under which it is ethical to dispose of abandoned embryos (32), we found no evidence to suggest that patients view having fewer embryos in storage as a benefit to them. Nevertheless, one strategy to reduce the number of stored frozen embryos has been

the establishment of legislation or regulation limiting the amount of time embryos can be stored. In some countries such legislation has resulted in large scale embryo disposal (16,33). Another effective, albeit unpopular, approach to encourage embryo disposition is through raising storage fees (34).

A third strategy for reducing the number of embryos stored in IVF clinics follows from our observations that embryo-holders have expectations of support for embryo disposition, and that the effective delivery of information may need to address a range of preferences with respect to timing, format, and content. These observations suggest that embryo-holders could benefit from (a) the delivery of comprehensible and detailed written materials about all disposition options at the time of embryo cryopreservation and subsequently at regular intervals as long as there are embryos in storage (b) regular communication about stored embryo number and viability, (c) comprehensive description of embryo storage fees including the terms of storage and conditions under which fees would change (d) identification of a knowledgeable medical person with whom to speak by phone, and (e) provision of in house or third-party counseling. These policies would not only assist embryo-holders to navigate the emotional and logistical complexities of disposition decision-making, but may result in fewer stored or abandoned frozen embryos by facilitating and streamlining the procedures for embryo donation.

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Table 1**Participant Demographics, Embryo Storage, and Disposition Decisions**

Embryo-holding families		
Total	106	100%
Participating as Couples	78	74%
Participating as Individuals	28	26%
Individuals interviewed		
Total	184	
Women	110	60%
Men	74	40%
Children		
Median number of children per family	2 (0–5)	
Median age of oldest child	4 (1–35)	
Age	Women	Men
Median Age	41 (31–57)	43 (26–69)
Marital Status		
Married	91	86%
Same Sex Couples	6	6%
Separated, Divorced, Widowed	5	5%
Single	4	3%
Ethnicity		
Caucasian	179	89%
Hispanic/Latino	7	4%
African American	1	1%
Asian	4	2%
Multi-racial	6	3%
No ethnicity reported	3	1%
Religion		
None, No religion reported	82	39%
Protestant	47	22%
Catholic	47	22%
Jewish	35	17%
Income		
Median Household Income	\$ 120,000	
Education		
High School	4	2%
Some College	27	13%
College	69	33%
Post Graduate	96	46%
No education reported	12	6%
Embryo Storage		
Median number of embryos in storage	6 (1–28)	
Median number of years in storage at end of study	5 (2–13)	

Average annual storage fee	\$495 (\$100-\$1500)	
Disposition Decisions		
Storage (Deliberate)	26	24%
Storage (Indecision or disagreement)	22	21%
Donate to science	42	39%
Attempt additional conception	6	6%
Donate to others for family-building	7	7%
Discard	3	3%