

# Are health care providers adequately educating couples for embryo disposition decisions?

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**Objective:** To determine the effectiveness of education provided by health care professionals during and after IVF treatment in preparing couples for surplus embryo disposition decisions.

**Design:** Cross-sectional survey.

**Setting:** University-affiliated fertility center.

**Patient(s):** Couples with embryos cryopreserved for more than 2 years.

**Intervention(s):** Self-administered questionnaire.

**Main Outcome Measure(s):** A Likert scale was used to rate the response to questions about patients' preparedness to make decisions regarding their surplus embryos.

**Result(s):** The survey response rate was 70% (131 of 187). Education provided by health care professionals before initiating treatment met the needs of the majority of participants ( $n = 86$ ). After treatment, the education received was not adequate to assist couples in making embryo disposition decisions. Of the 127 respondents who provided feedback on their intention for their cryopreserved embryos, 37% ( $n = 47$ ) had no intention of using cryopreserved embryos for their own reproduction, 24% ( $n = 30$ ) intended to use embryos for procreation, and the remaining 39% ( $n = 50$ ) remained undecided regarding their future use of their embryos. Participants with more than 3 years of infertility ( $n = 49$ ) were most likely to feel conflicted about the decision after treatment.

**Conclusion(s):** The education received after treatment was considered inadequate. Couples with a long duration of infertility and those conflicted about final embryo disposition may be appropriate targets for further intervention. More written information and/or counseling services after treatment may help patients make informed and timely decisions regarding their surplus embryos. (Fertil Steril® 2016;105:684–9. ©2016 by American Society for Reproductive Medicine.)

**Key Words:** Abandoned embryos, embryo cryopreservation, embryo end disposition, supernumerary embryos, surplus embryos

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One of the biggest paradoxes of successful IVF is that it often leaves patients with an unexpected and serious problem: what to do with their surplus embryos. Currently there is no Canadian national registry to ascertain the exact number of cryopreserved embryos in this coun-

try. The most recent population survey occurred in 2003, from which it was estimated that there were roughly 15,000 embryos stored in 13 clinics across the country (50% survey response rate) (1). Since 2003 the number of fertility clinics has almost tripled, and demand for fertility services has

also dramatically increased. We can hypothesize that the number of cryopreserved embryos has doubled, if not tripled. Most stored embryos are cryopreserved with the intent of using them in subsequent IVF treatments by the couple who created them. As the success of IVF treatments improves and surplus embryos become more common, finding solutions to help patients make timely embryo disposition decisions is a continually growing challenge.

Prolonged storage of cryopreserved embryos can create logistical and ethical dilemmas for patients and

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fertility clinics. It is estimated that approximately one-third of patients will not return to provide medical directives for their embryos (2). Currently four options are available in Canada for surplus embryo disposition: ethical disposal/destruction; donation to research; donation for the purposes of teaching/training; and embryo donation to a third party (3). The process of ethical disposal involves thawing embryos in conditions that allow the embryo to perish. Alternatively, patients may opt to have their embryos used for research that is in accordance with the regulations set by the Assisted Human Reproductive Act (3). Embryos remain cryopreserved until a research initiative gains ethical approval, at which point the patient would be notified of the study details and invited to participate and consent to the specific research project. Donation for teaching/training initiatives allocates embryos to the education of embryologists, ensuring that technical skills meet standards to optimize patient care. Embryo donation transfers ownership of the embryo(s) to a third party while relinquishing the patient of any ongoing responsibility for the offspring. Many different structures of embryo donation programs exist that allow both parties to receive varying degrees of information about each other.

The Assisted Human Reproduction Act of Canada (2007) stipulates that written patient consent is required before the creation or disposal of embryos (3). Once fertility treatment is complete, many patients fail to return to provide directives for the disposition of their surplus embryos. Consequently, many embryos remain in storage indefinitely. Interventions that would assist patients in making informed decisions that respect their values would add to the quality of care and at the same time simplify the clinic's management of cryopreserved embryos and decrease the number of embryos in indefinite storage.

Previous publications have focused on the decision-making process, as well as patients' attitudes toward various embryo disposition options, highlighting the conflicting and emotional nature of patient decisions around the disposition of supernumerary embryos (2–5). The present study's primary objective was to determine whether the education provided by the health care team before and after IVF treatment was adequate to prepare patients to make informed decisions regarding the subsequent disposition of their surplus embryos. Education involved physician-directed individual teaching regarding the disposition options, as well as psychosocial counseling provided by a physician, nurse, or psychiatrist.

## MATERIALS AND METHODS

All couples had received some formal counseling regarding the potential for supernumerary embryos before commencing an IVF treatment cycle. In addition to a 1-hour IVF group teaching session, couples were counseled individually; during both sessions, embryo disposition was addressed, and patients were encouraged to consider their wishes for the disposition of surplus embryos resulting from their treatment. This education included the provision of verbal information describing the available disposition options and answers to patients' questions

regarding their options. The patient consent document for IVF treatment or any subsequent frozen embryo treatment specifically addressed the issue of disposition, asking patients to consider the available options and to indicate their preference.

Couples with embryos stored for 2 years or longer at The Ontario Network of Experts in Fertility (ONE Fertility), Burlington, were contacted by telephone to discuss the nature of the study and were asked if they might be interested in participating. Embryo storage for 2 years or more was used as a cut-off to maximize sampling of patients who were actively contemplating embryo disposition.

Participants were able to contact the primary investigator at any point by e-mail or telephone to request further information about the study before participation. Those agreeing to participate were sent an information package by e-mail/post or were interviewed in person by the primary investigator, to discuss the study. The information package included a description of the study, a personal identification number, and a link to an electronic survey. Personal identification numbers were used to track survey completion. All responses remained anonymous. Participants were given the option to respond to the survey independently or as a couple. The survey took 30 minutes to complete. Where necessary, participants were sent e-mail reminders once weekly for 3 weeks and a follow-up telephone call to improve response rate.

The survey was developed and reviewed before use by a team of reproductive endocrinologists, an embryologist, and an epidemiologist, to ensure appropriateness of content and process. The survey consisted of 24 items, primarily closed-ended questions that included patients' age, relationship status, fertility treatment history, and evaluation of the education provided before and after fertility treatments, as well as the perceived barriers to the currently available disposition options. A Likert-type scale was used to rate the response to questions about patients' preparedness to make decisions regarding their surplus embryos, based on the education they received (not at all, somewhat informative, adequately informative, and extremely informative). To identify barriers that may contribute to the decision to continue embryo storage, patients were asked to select the descriptor(s) that best represent their perspective (4, 6–8).

This study received approval by the Hamilton Integrated Research and Ethics Board of McMaster University before initiation (protocol no. 14–495).

We examined frequencies of responses for demographic characteristics, satisfaction with the education provided, and perceived barriers to embryo disposition decisions. Responses were subdivided into three categories; intention to use embryos for personal reproduction, undecided about future reproductive use, and participants who store embryos with no intention of further IVF treatments. Chi-squared tests and analysis of variance were used to determine whether these subgroups were significantly different. When numbers were small ( $n < 5$ ), a Fisher exact test was used to compare groups.

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