New approach to IVF embryo donations lets people weigh decision

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People who use in vitro fertilization to conceive children often have leftover embryos and must decide whether to store them, dispose of them or possibly donate them for research. A new process developed by researchers at the Stanford University School of Medicine allows these people to make this decision in the privacy of their own homes - without any interaction with clinic personnel or scientists who might benefit from the research.

"There is concern that conflicts of interest and influence by researchers and clinicians may play a role in donor choice," said bioethicist and senior author of the research, Christopher Scott, who directs Stanford's Program on Stem Cells in Society. "The Stanford biobank process allows people time to make the primary decision to donate on their own, when it's right for them. It also allowed us to ask whether donors have preferences as to the type of research they will allow on their embryos."

The study will be published April 8 in *Cell Stem Cell*. The study includes a description of the process as well as the results of a survey indicating which research options were selected by those who chose to donate their embryos.

People who try in vitro fertilization often find themselves with excess embryos after they either successfully conceive or abandon their attempt to have children. Researchers believe that at least several hundred thousand are stored in clinics around the country. There is routinely a monthly or yearly storage fee to keep the embryos frozen in liquid

nitrogen.

Many IVF clinics offer people the option of donating their embryos for research, but the procedures vary and often involve discussions between potential donors and experts as part of the decision-making process. Many also do not specify the types of research for which the embryos could be used.

In the two-part procedure described in the study, which is now used routinely at Stanford, information about potential donation for research is included in the normal embryo-storage bill from the clinic. "At that point," Scott said, "the recipients are free to throw the information away or put it on the coffee table to consider and talk about." Only after the couple has made the initial decision to donate do they interact with Stanford biobank staff members, who use a script to confirm donation choices and answer any questions the potential donors may have.

Specifically, people who indicated that they would like to donate were sent an informed-consent packet outlining the types of research that could be done with the embryos, such as creating embryonic stem cell lines or studying human development. (Research into human development typically occurs during the first 12 days of culture, after which the embryos are no longer grown. Embryonic stem cell research entails creating stem cell lines that can be propagated indefinitely in the laboratory and may be used for both research and therapy.)

Once the potential donors had time to review the material, they then participated in a phone interview with staff members at Stanford's biobank who were unconnected with either the original in vitro fertilization clinic or the researchers who might use the embryos. Staff members followed a script to confirm the donors' preferences and make sure they understood their options - including whether they wanted to be notified if the research unearthed any genetic information that might

affect their health or the health of their relatives.

"Many couples were very relieved to have the option to donate their embryos for research and to participate in the field of stem cell research," said Stanford biobank research manager and study first author Tasha Kalista.
The researchers found that donors were equally likely to give consent for their use in the creation of embryonic stem cell lines as for the study of human development.

In addition to outlining the new process, the paper also reports on the preferences of the participants. The researchers found that people who choose to donate their embryos for research are primarily concerned that they not be used to make a baby for someone else. Although people have the option to put their embryos up for "adoption," that is an entirely separate process from donating an embryo for research purposes. Nonetheless, many donors asked for reassurance.

The researchers did not have sufficient data to determine what proportion of potential donors chose to either continue storing their embryos or to dispose of them.

The researchers surveyed the preferences of 403 couples who donated 1,356 embryos to Stanford for research. The embryos had been stored at one of 40 in vitro fertilization clinics or three storage facilities in 20 states. About one-fifth of those surveyed had used donated eggs or sperm and were excluded from further analysis because consent for embryonic stem cell research would have also been required from the egg and sperm donors. Of those remaining, 32 percent gave consent for their embryos to be used only for the study of human development and 30 percent only for stem cell research. Thirty-eight percent gave consent for their embryos to be used for either type of research.

In the future, Scott and the other researchers would like to determine what proportion of potential donors choose to give embryos for research. They'd also like to find out if donors' choices are influenced by where they live.

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