

# **Attitudes and Beliefs About Embryo Donation in a Population Inquiring at an Embryo Donation Program**

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## Summary

**208 (24.2%) couples who had inquired about embryo donation at National Embryo Donation Center responded to a mail-in 22-item questionnaire. Of these, 161 (77%) were committed to donate their remaining embryos to other couples; 37 (23%) already had. Of committed donors, 66 (41%) preferred a totally open arrangement; some others desired limited information sharing. “Helping another couple” and “giving the embryos a chance at life” were the most common reasons for wanting to donate. About half the couples saw donation as “relinquishment of a child”, but many preferred to think of it as “gift of a potential child”.**

## Introduction

Following the advent of in vitro fertilization (IVF) in 1978 and the subsequent development of embryo cryopreservation techniques in the 1980s, couples who have used these therapeutic modalities have asked themselves what to do with embryos that they no longer intend to use. For some, donation of the embryos for adoption by another couple is seen as an attractive option. In embryo adoption, the transfer of custody of the embryos from the giving to the receiving couple occurs under contract law, not under child adoption law. However, the term “embryo adoption” resonates with the adopting couple because they are preparing to parent a child not of their own genetic background – just as “embryo donation” resonates with the donating couple because they

are “giving a gift of life”. In this report, we use either or both terms depending on the context. Following the legal transfer of custody, the embryos are then physically transferred to the recipient woman in a clinical setting using a procedure quite similar to that used when a woman’s own embryos are placed following in vitro fertilization.

Both donation to research and donation to another couple make some use of embryos, which have required much emotional and financial effort to create. However, donation to another couple also represents an opportunity to give a gift to others who have gone through a similar struggle with infertility. Finally, for those who see the embryo as an already-created human person, it is the only option besides trying for another child that gives the embryo a chance at life.

The National Embryo Donation Center (NEDC), in Knoxville, Tennessee, is the only clinic-based national organization that facilitates embryo donation and adoption for couples across the United States. NEDC is a private, non-profit organization which receives federal grant support to research and promote embryo adoption, though not to render the clinical services. Embryo adoptions are also carried on by adoption-agency based organizations and sometimes, between couples attending individual infertility clinics. Generally, couples who wish to donate their embryos are matched with couples wishing to adopt, based on criteria specified by the respective couples. At NEDC, approximately 55 percent of transfers successfully result in a pregnancy.

Some embryo adoptions are entirely anonymous, some are completely open, in which the families form relationships, and others are somewhere in between, where couples may know significant facts about each other's lives and histories, but not identifying or locating information. NEDC offers all three types of embryo adoption. In its five years of operation, NEDC has had inquiries from more than 800 couples with cryopreserved embryos. Over 300 of these have actually donated their embryos, and more than 200 embryo transfers have been performed. More than 100 babies have been born so far as a result of this program.

A couple adopting embryos goes through a preparation process not unlike that faced by a couple undertaking traditional adoption. Thus, a study of the issues confronting both donating and adopting couples is informed to an extent by the decades of experience with traditional adoption families. For instance, relinquishment of a child has been found to lead to a wide variety of feelings and experiences on the part of the birth parent in later life (1-3). Adopted children often seek to find out about, and sometimes to establish relationships with, their birthparents (4-5). The trend in recent decades toward "open" vs. "closed" adoption has also been well documented (6-7). We explore issues parallel to these in the discussion.

Meanwhile, several authors worldwide have explored the attitudes of individuals and couples toward the different options for embryo disposition, and toward embryo donation to other couples, in particular. Lornage and colleagues in France observed that 32 of 145 couples with remaining embryos initially wanted to donate them to other couples, but eight of them changed their minds when the time came (8). They did not study the specific reasons for the couples'

choices. Hammarberg & Tinney in Australia found that 20 of 123 couples in their clinic-based sample chose donation to others, a smaller fraction than chose donation to research or destruction (9). All those choosing donation wanted to help other couples conceive; about two thirds of those also wanted to give embryos a chance at life.

The most detailed published study of couples' attitudes and beliefs about the disposition of embryos has been that of Sheryl de Lacey in Australia (10). Forty-eight patients (16 women and 16 couples) who had made a recent decision either to donate or to destroy embryos were studied. They participated in an interview which was transcribed and coded using an elaborate qualitative research design. A number of comments from individual participants are included in the paper. The key finding was that both those who donated embryos and those who discarded them were driven primarily by a metaphor relating to the option they did *not* want. Specifically, those who chose donation saw destruction as akin to abortion, and those who chose discard saw donation as akin to relinquishing a child.

McMahon & Saunders, also in Australia, found that a small minority of survey respondents wanted to donate to other couples, but that this percentage was likely to increase substantially if the couple could place some conditions on who might receive the embryos (11).

Lyerly and colleagues describe findings from 1,020 respondents who have embryos in frozen storage, from 9 U.S. fertility clinics (12). Though the subjects who thought it "very likely" or

“somewhat likely” that they might donate their embryos were a minority in their study (22 percent), it still represents a reasonably sized pool of potential donors. In the Lyerly study, altruistic motivation and a positive view of the moral status of the embryo correlated with wanting to donate.

The findings of Provoost and colleagues in Belgium were similar (13). In this study, the couples’ sense of a genetic link to the embryo, and the embryo as a symbol of the couple’s relationship, were linked with a reluctance to donate. The authors observed that most couples went through a two-stage sequence in making a decision about their embryos.

We questioned what attitudes toward donation or destruction might exist among those people with remaining embryos who had inquired with NEDC – and what metaphors might influence those attitudes. We realized from the outset that our population would have views different from those in other studies because they initiated inquiry with NEDC, an organization known to take a pro-embryo donation perspective. Our purpose was to find out *why* our inquirers differed from others and what factors led to their espousing the attitudes and beliefs that they did.

## **Methods**

We created a 22-item questionnaire designed to discover the attitudes and beliefs about embryo donation in those individuals with remaining embryos who had inquired with NEDC. The questionnaire asked whether or not these couples had eventually gone on to donate, through

NEDC or elsewhere. Other than demographical information, we also included questions about religious background, educational level, and number of children conceived by IVF, to see if any of these factors correlated with attitudes about embryo donation. We then presented a list of possible metaphors and asked which of them most closely related to embryo donation in the individual's mind. The questionnaire and study were approved by the University of Tennessee Medical Center Institutional Review Board. The IRB declined to approve a question asking about metaphors related to embryo destruction. Hence, we were not able to gather information on this topic.

Beginning in May 2008, questionnaires were mailed to 860 couples who had been listed by NEDC as having inquired about donation. Those who did not respond to the first letter were sent a second mailing approximately six weeks later. Although our protocol indicated that we would contact non-responders by telephone, we declined to do so after receiving phone calls from about eight recipients who were, for various reasons, unhappy about receiving the questionnaire. From June through December, we entered responses received by mail into an Excel file and analyzed the results. In some cases, responses were recoded for consistency using all the information, including comments, received on the questionnaire.

## **Results**

We received 208 responses from 41 states, for a response rate of 24.2 percent. One response was received per couple. We made no attempt to distinguish which member responded for the couple. The average age of the male partner was 43.3, of the female partner, 40.9; within a

couple, the average difference in age was 3.7 years. 201 of the 206 couples who disclosed their marital status (97.6%) were married; these had been married an average of 11.3 years. This was a very well-educated cohort: 38.5% of the men and 41.3% of the women had done graduate work, and an additional 33.2% of men and 30.8% of women had achieved a bachelor's degree. Religious affiliation is listed in table 1. Roughly half the group related to a Protestant Christian tradition; another third were Roman Catholic, either alone or in combination with another tradition; smaller numbers represented other traditions. 32 respondents (15.4%) had no religious tradition or left the response blank. Couples had anywhere from no children to five or more; most of these children had been conceived through IVF (Table 1).

Forty-three (20.7%) couples had already donated embryos, the majority of these through NEDC. The respondents with embryos remaining reported that they had an average of 5.6 embryos in frozen storage for an average of 4.5 years.

From their responses to the level of acceptability to each of 5 embryo disposition options, couples were classified either as having definitely chosen an option, as leaning toward an option, or as undecided. 77 percent were committed donors (meaning they marked "Donation to another couple" as "our definite choice for the embryos"); 23 percent had already donated. For definite or leaning couples, their opinions of the remaining options were classified as either "possibly acceptable" or "not acceptable". Undecided couples were those for whom all the options were classified as either "possibly acceptable" or "not acceptable". A summary of the couples' disposition options is given in Table 2.

From their responses to the questions about open vs. closed donation, the couples who had definitely decided to donate were grouped into six donation preference groups. These are seen in the lower half of table 2. The options “totally open”, “select from profile but no identities” and “allow clinic to place for you anonymously” were offered in the questionnaire. Several respondents checked “other” and described an “in-between” or a differing option. Two more themes (“identities known but limited communication” and “anonymous, some criteria specified”) were identified this way and included in table 2.

Because the majority of these respondents were at least neutral if not favorable toward embryo donation, it was useful to calculate a “commitment percentage” – that is, the percentage of respondents who had definitely decided to donate their embryos or who had already done so – in the demographic subgroups. Table 3 shows the results of this analysis for five demographic variables. Religious affiliation did not greatly affect commitment percentage, except that those who did not list an affiliation had a somewhat lower level. In addition, the commitment percentage was similar in those who had embryos frozen for more than 5 years (80%) and those who had embryos frozen for less than five years (82%).

The couples committed to donate embryos were also classified as to their reasons for wanting to donate (table 4). In this question, no options were specified, but all the categories were derived from themes expressed by the respondents. There was a relatively even balance between reasons relating to the other couple (such as “identify with infertility struggle”) and reasons relating to

the embryo (such as “save the embryo”). One couple wrote in that they wanted to donate because they no longer wanted to pay storage fees. In these analyses, couples who had already donated did not differ substantially from the larger pool of committed donors.

All the responding couples in the study were grouped as to their sense of what most defines a family (table 5). Here the options “genetic relatedness” and “interpersonal bonding” were offered. Respondents overwhelmingly chose the latter option. Eleven respondents wrote in “both”, and seven expressed a theme related to traditional marriage or faith commitment as the basis of a family in their comments.

Each respondent was asked for the metaphor which, to him or her, most closely describes what embryo donation is like (table 6). “Donating tissues or organs to another person” and “relinquishing a child for adoption” were offered as options. A majority (51%) of all respondents identified with the latter option. 16% wrote in their opinion that embryo donation was more akin to “gift of a potential child”. Eleven respondents wrote “in between” in their comments; and 15 expressed one of several other metaphors. The metaphors selected were similar among committed donors, actual donors, and the group at large.

## **Discussion**

The most important finding of this survey is that there are many couples with embryos remaining from IVF procedures who want to donate them to other couples and are not comfortable with

other disposition options. The response rate, though it falls within the range of other published surveys, is too small to reliably represent all the eight hundred who initiated inquiry to NEDC. However, 41 different states and a variety of age groups, religious backgrounds, and personal fertility experiences were represented among the respondents (see tables). Our respondents have a unique perspective on what embryo donation means, and predominantly want to donate for positive reasons reflecting broad social values – to help other couples who have gone through a similar infertility struggle, and to give the embryo a chance at life.

The metaphor for embryo donation “like relinquishment for adoption” was chosen by a majority of committed donors as well as a majority of respondents overall. This contrasts with de Lacey’s finding that this metaphor was associated with NOT wanting to donate (10). Interestingly, however, a large minority chose neither relinquishment nor tissue donation as an appropriate metaphor, but rather “the gift of a *potential* child”. Thus, support for embryo donation is not limited only to those who see saving the embryo as a moral imperative because they believe that a person is created at fertilization. The “gift of a potential child” group is all the more noteworthy considering that this option was not listed on the questionnaire, but rather *written in* by so many people.

We found that at least half of potential donors would prefer an arrangement where the couples at least exchange identities, if not embark on a family-to-family relationship. About half of couples who actually donate at NEDC prefer open donation. This experience parallels McMahon’s observation that conditional donation increases the percentage of couples willing to consider

donation (11). We recommend that when infertility clinics discuss disposition options with couples, they describe anonymous, open, and in-between options for donation to other couples and make it clear that any of these options could be chosen.

We did not have enough respondents who chose destruction or donation to research as a preferred option, to evaluate whether these groups viewed donation to other couples as like relinquishment, or something else. Nor did we have the opportunity to evaluate whether destruction of an embryo was seen as similar to abortion.

We found that respondents' disposition choices, reasons for those choices, and metaphors were essentially independent of demographic subgroup. In terms of religious affiliation, support for donation was consistent across the Catholic, Protestant, and Jewish subgroups represented among our respondents. Some of the subjects stated that they held the views they did because of religious conviction. We did not have enough respondents from outside the Jewish and Christian traditions to reliably evaluate their choices.

Our study was limited in that we did not ask what options for disposition of embryos were offered to our respondents when they first underwent IVF. Individuals' preferences are known to change between the time the embryos are created and the time a disposition is made (8, 13). NEDC has found that some small fertility clinics do not offer the option of donating embryos to other infertile couples on their consent forms. Thus, some couples with remaining embryos may

not have considered embryo donation because they never heard of it. These couples are unlikely to be represented either in studies conducted at research centers, or in studies of inquirers, such as ours. We believe that the broadly targeted public and professional education efforts of NEDC and its sister agencies nationally can be effective at reaching some of these couples.

We recommend that each couple consider a structured counseling and educational session in order to help them make a timely, reasoned decision about what to do with their embryos. Infertility clinic professionals must remember to assess the couple's reasons for the choices they are considering, as well as explore their metaphors both for donation and destruction of the embryos. NEDC is currently conducting a follow-up study of the responders to this questionnaire to determine how well they were helped by NEDC's educational efforts when they inquired. Further research is also needed to explore how variation in the way different clinic staffs present options to couples affects their decisions.

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**Table 1 – Characteristics of Inquirers to NEDC About Embryo Donation**

Religious Affiliation	Number of Inquirers	Percent of Inquirers
None or blank	32	(15.4%)
Jewish	8	(3.8%)
Jewish in combination	3	(1.4%)
Other than Jewish or Christian	4	(1.9%)
Catholic	54	26.0%
Catholic in combination	12	(5.8%)
Lutheran or Lutheran in comb.	15	(7.2%)
Baptist or Baptist in comb.	18	(8.7%)
Other Christian traditions	62	(29.8%)

Number of Children	Couples With This Total Number (%)	Couples With This Number of Children by IVF(%)
0	2 (1.0%)	20 (9.7%)
1	35 (16.8%)	68 (32.9%)
2	87 (41.8%)	81 (39.1%)
3	60 (28.9%)	33 (15.9%)
4	17 (8.2%)	5 (2.4%)
5 or more	7 (3.4%)	0 (0.0%)

**Table 2 – Preferences Chosen by Inquirers to NEDC About Embryo Donation**

Disposition Preference Chosen	Number of Inquirers	Percent of Inquirers
Definitely decided to donate	161	(77.4%)
Destruction unacceptable	133	(82.6%)
Research unacceptable	84	(52.2%)
Already donated	37	(23.0%)
Leaning to donate	22	(10.6%)
Destruction unacceptable	14	(63.6%)
Research unacceptable	7	(31.8%)
Definitely decided to destroy	4	(1.9%)
Leaning to destroy	2	(1.0%)
Definitely decided research	5	(2.4%)
Leaning to research	3	(1.4%)
Definitely decided to freeze indefinitely	1	(0.5%)
Undecided	6	(2.9%)
No preference information given	4	(1.9%)
Donation Policy Preferred	Number (%) Among Committed Donors	Number (%) Among Actual Donors
Totally open	66 (41%)	18 (48.6%)
Identities known but limited communication	12 (7.5%)	3 (8.1%)
Select from profile, no identities	21 (13.0%)	5 (13.5%)
Anonymous, some criteria specified	6 (3.7%)	
Totally anonymous	48 (29.8%)	10 (27.0%)
None of the above	6 (3.7%)	
No preference information given	2 (1.2%)	1 (2.7%)

**Table 3 – Commitment Percentage in Demographic Subgroups Among Inquirers to NEDC About Embryo Donation**

Demographic subgroup	Fraction Committed to Donate
Husband has graduate work	64/79 (81.0%)
Husband has bachelor's degree only	49/67 (73.1%)
Husband has some college	29/34 (85.3%)
Husband is HS grad only	17/18 (94.4%)
Wife has graduate work	62/79 (78.5%)
Wife has bachelor's degree only	45/60 (75.0%)
Wife has some college	39/45 (86.7%)
Wife is HS grad only	13/14 (92.9%)
Couple married 16 years or more	25/30 (80.0%)
Couple married 11-15 years	42/57 (73.7%)
Couple married 6-10 years	54/66 (81.8%)
Couple married 1-5 years	19/23 (82.6%)
Jewish religious preference	9/11 (81.8%)
Catholic religious preference	52/62 (83.9%)
Other Christian religious preference	76/92 (82.6%)
Other religious preference	4/4 (100.0%)
No religious preference expressed	20/32 (62.5%)
Couple's combined age <40 (teens)	0/2 (0.0%)
Couple's combined age 40-59 (20s)	6/9 (66.7%)
Couple's combined age 60-79 (30s)	55/73 (75.3%)
Couple's combined age 80-99 (40s)	81/94 (86.2%)
Couple's combined age 100-119 (50s)	15/17 (88.2%)
Couple's combined age 120-139 (60s)	2/3 (66.7%)
All inquirers combined	161/208 (77.4%)

**Table 4 – Reasons for Wanting to Donate in Committed & Actual Donors Among Inquirers to NEDC About Embryo Donation**

Reason for Wanting to Donate Embryos	Number (%) Among Committed Donors	Number (%) Among Actual Donors
Do not want to destroy embryo	5 (3.1%)	2 (5.4%)
Give embryo a chance at life	15 (9.3%)	2 (5.4%)
Help another couple	31 (19.3%)	4 (10.8%)
Relate to another couple's infertility	7 (4.3%)	2 (5.4%)
Do not destroy AND help another couple	2 (1.2%)	2 (5.4%)
Chance at life AND relate to infertility	3 (1.9%)	0 (0.0%)
Chance at life AND help another couple	8 (5.0%)	1 (2.7%)
Other reason	14 (8.7%)	2 (5.4%)
Stated decision or action but no reason	26 (16.1%)	10 (27.0%)
No reason information given	50 (31.1%)	12 (32.4%)

**Table 5 – Sense of What Defines a Family Among Inquirers to NEDC About Embryo Donation**

Family-defining Factor Chosen	Number of Inquirers	Percent of Inquirers
Genetic relatedness	4	(1.9%)
Interpersonal bonding	176	(84.6%)
Both genetic and interpersonal	11	(5.3%)
Faith commitment or traditional marriage	7	(3.4%)
Other	1	(0.5%)
No information given	9	(4.3%)

**Table 6 – Metaphor for Embryo Donation Among Inquirers to NEDC About Embryo Donation**

Metaphor Preferred	Number (%) of All Inquirers	Number (%) of Committed Donors	Number (%) of Actual Donors
Organ or tissue donation	30 (14.4%)	23 (14.3%)	7 (18.9%)
Relinquishment of child for adoption	106 (51.0%)	82 (60.9%)	14 (37.8%)
In between	11 (5.3%)	7 (4.3%)	4 (10.8%)
Gift of potential child	35 (16.8%)	31 (19.3%)	7 (18.9%)
Other metaphor	15 (7.2%)	12 (7.5%)	1 (2.7%)
No metaphor selected or expressed	11 (5.3%)	6 (3.7%)	4 (10.8%)