Patient attitudes to donation of embryos for research in Western Australia

Peter J Burton and Katherine Sanders

ABSTRACT

Objective: To ascertain patients' attitudes to embryo donation for research purposes.

Design: Anonymous questionnaire survey.

Participants and setting: 235 couples who had embryos in storage at Concept Fertility Centre on 30 March 2003 that had been cryopreserved between 1 January 2000 and 30 June 2002.

Main outcome measures: Participants' choices with regard to donating embryos to another couple, to research to improve in-vitro fertilisation (IVF) techniques or to stem-cell research, and the likelihood of couples choosing to use a range of sources to help them with their decision.

Results: The response rate was 57%. Twenty-nine per cent of respondents (36/126) reported they would donate their embryos to research that would improve IVF techniques and 27% (34/126) reported they would donate their embryos to stem-cell research. Fifteen per cent (19/126) would donate their embryos to another infertile couple. Willingness to donate to research was not influenced by whether the couple had previous children, or age. Women and men with moderate to strong religious beliefs were less likely to donate to research. Over 90% of respondents indicated they would seek outside help to decide the fate of their embryos.

Conclusion: This study suggests that about 30% of couples would donate their embryos to research, and highlights the need to provide support and information to help couples through their decision-making process.

MJA 2004; 180: 559–561

EMBRYO CRYOPRESERVATION has become an integral part of in-vitro fertilisation (IVF) procedures since the first pregnancy from a frozen–thawed embryo was reported in Melbourne in 1983.[1] Controlled ovarian hyperstimulation results in around 10 mature oocytes being available for IVF, and any embryos surplus to the patient's immediate needs can be frozen, stored and used in subsequent treatment cycles. It has been estimated that over 80 000 embryos are in storage in Australia;[2] in the United States, there are over 400 000.[3] The vast majority of these stored embryos will be used by patients in their treatment.[3-6]

The length of time embryos can remain in storage is subject to legislation, which, in Australia, varies by state.[7] In Victoria, there is a 5-year storage limit with some provision for extension, whereas in South Australia and the Northern Territory a 10-year limit with no extension is in place. States without specific legislation, such as New South Wales and Queensland, follow the Reproductive Technology Accreditation Committee guidelines,[8] which stipulate a 10-year limit to embryo storage. In Western Australia, the legal limit for embryo storage is 3 years, after which storage extensions for 2-year periods are granted by the Reproductive Technology Council.

As the end of the legal time limit approaches, couples must decide the fate of any of their embryos still in storage. In Western Australia, couples can choose (i) to use the embryos in a treatment cycle, (ii) to apply for a storage extension, (iii) to donate the embryos to another couple, or (iv) to discard their embryos. In our centre, 64% of couples decide to extend the storage, while 19% wish to discard their embryos, and 6% donate to another couple.[6]

Although the option of donating stored embryos to research is currently unavailable in Western Australia, amendments to the *Reproductive Technology Act 1991* (WA) may allow couples to donate their surplus embryos to research. This would allow either stem-cell research, or embryo research to improve IVF technology. Patient attitudes to embryo donation for research in Western Australia have not been investigated. Therefore, the main objective of our study was to ascertain the proportion of couples willing to donate their embryos to research, in particular to research involving stem cells or to improve IVF techniques.

Concept Fertility Centre, King Edward Memorial Hospital, Perth, WA.
Peter J Burton, PGDip(Sci), PhD, Scientific Director.
School of Anatomy and Human Biology, University of Western Australia, Perth, WA.
Katherine Sanders, BSc(Hons), PhD, Lecturer.
Reprints will not be available from the authors. Correspondence: Dr Peter J Burton, Concept Fertility Centre, King Edward Memorial Hospital, PO Box 966, Subiaco, Perth, WA 6904.
pete@conceptfert.com.au

METHODS

Approval for this research was granted by the King Edward Memorial Hospital Institutional Ethics Committee.

An anonymous survey was sent to 235 couples who had embryos in storage at Concept Fertility Centre on 30 March 2003 that had been cryopreserved between 1 January 2000 and 30 June 2002. The initial survey was sent on 1 May 2003 and a reminder letter and survey were sent to all couples 3 weeks later. The survey consisted of two parts to be answered anonymously. The initial section sought demographic information — sex, current marital status, age, strength of religious beliefs and whether there were any children in the relation-

1: Couples' attitudes to donation of stored embryos

Willingness to donate embryos to	Yes	No	Don't know	Couples disagreeing*
Another couple	19 (15%)	47 (37%)	11 (9%)	49 (39%)
Research to improve IVF techniques	36 (29%)	33 (26%)	12 (9%)	45 (36%)
Stem-cell research	34 (27%)	33 (26%)	16 (13%)	43 (34%)

IVF = in-vitro fertilisation.
* Value includes responses when they came from only one member of the couple.

ship. The second section ascertained whether couples would donate their embryos to another infertile couple, to research to improve IVF techniques or to stem-cell research. Response options were "yes", "no" or "don't know". Couples were also asked how likely they were to use a range of different sources to help with the decision about the fate of their stored embryos. Response options for this question were "very likely", "may use", or "would not use". Partners could respond separately. Participants were invited to add comments after each question.

As, legally, the decision to donate embryos must be agreed upon by both members of the couple, female and male partner responses to the questions concerning embryo donation were cross-tabulated.

To examine whether age, having previous children in the relationship or strength of religious beliefs influenced the decision to donate, independent sample t tests and χ^2 analyses were performed.

RESULTS

For the 235 questionnaires sent, 15 intended recipients could not be found at the recorded address and 126 returned completed questionnaires, giving a response rate of 57%. Respondents comprised 109 couples and 17 women. Two respondents were not currently in a marital relationship; one was widowed and one separated. The average age of all women who responded was 34.8 years (SD, 4.9 years), and, for men, it was 38.3 years (SD, 6.6 years). One hundred and five respondents (83.3%) had a child in the relationship; 83 of these children had been born as a result of assisted reproductive technology.

Donation to research

Overall, about 30% of participants reported that they would donate their embryos to research. Couples were more likely to be willing to donate their embryos to research than to another couple ($\chi^2 = 9.304$; $P = 0.009$) (Box 1). There was no difference between willingness to donate to stem-cell research or research to improve IVF techniques. Willingness to donate to research was not influenced by whether the couple had previous children ($\chi^2 = 0.117$; $P = 0.803$) or by individuals' age ($t = 0.701$; $P = 0.454$ for women, and $t = 1.418$; $P = 0.159$ for men). Women and men who held moderate to strong religious beliefs were significantly less likely to donate to research than those whose religious beliefs were not strong (Box 2).

2: Strength of religious beliefs and willingness to donate to research

Strength of religious belief	Willingness to donate: Yes	Willingness to donate: No	χ^2	*P*
Women				
None to not very strong	28 (42%)	38 (58%)		
Moderate to very strong	12 (20%)	48 (80%)	7.294	0.008
Men				
None to not very strong	31 (41%)	44 (59%)		
Moderate to very strong	9 (18%)	41 (82%)	7.506	0.01

Sources of assistance for deciding the fate of stored embryos

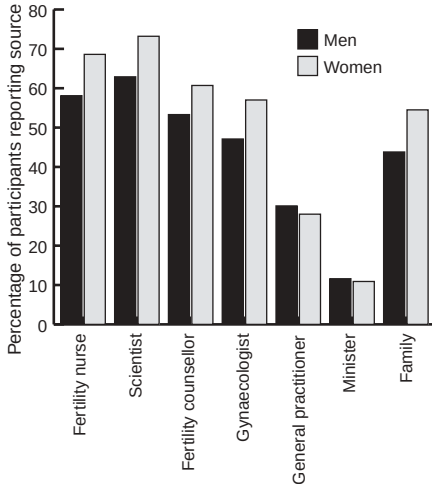
Over 90% of respondents indicated they would seek outside help to decide the fate of their embryos, with only six women and nine men saying they would not seek help (Box 3). Healthcare professionals with expertise in IVF were reported as most likely to be asked for assistance. There were no differences between men and women in their responses.

DISCUSSION

Embryo research is a sensitive topic that has been publicly debated in Australia and overseas in recent years. The main finding of our study was that nearly 30% of couples indicated that they would consider donating their excess embryos to research. This finding is consistent with those of a previous study which reported that 10% of couples from a Sydney IVF clinic indicated it was probable and 34% indicated it was possible that they would donate their embryos to research, and that 29% of patients from their clinic actually did donate embryos to research during 1986–2001.[9] Other studies have found less willingness to donate excess embryos to research. For example, a French study found that 12% of couples with embryos in storage after 5 years would accept donation of their embryos to research.[10] Interestingly, the preference for embryo donation to research is much higher in Sweden, where donation to another infertile couple is not permitted. There, 92% of couples surveyed preferred to donate their excess embryos to stem cell research rather than let them be discarded.[11]

We attempted to identify factors influencing couples' reported intention to donate embryos to research. Individuals' age and having children in the relationship did not influence their decision to donate to research, but those having strong religious beliefs were less likely to donate. A non-significant trend for those who were more religious to be less inclined to donate to research was also reported in the Sydney study.[9] We

3: Sources of assistance likely to be used to help couples decide the fate of stored embryos



found no preference for stem-cell research or research to improve IVF techniques, but respondents' comments indicated that some couples would need specific information about the type of research program proposed before considering donation. This is consistent with the Sydney study, which found that lack of control over the type of research was a major concern for couples.[9] Indeed, in accordance with the *Research Involving Human Embryos Act 2002* (Cwlth), the NHMRC guidelines for research involving human embryos stipulate that researchers must obtain specific consent for each research project.[12]

Our study shows that couples in Western Australia are more likely to donate embryos to research than to donate to another infertile couple. The reluctance of couples to donate their embryos to another infertile couple is at odds with the relatively high level of acceptance of this form of embryo donation in the general community.[13] However, 83% of the couples surveyed in our study had children in the relationship, and this has previously been shown to negatively influence parents' decisions to donate their embryos to other infertile couples. The major concerns reported in this and other studies[7,14] were the possibility of sibling marriage, having unknown children and the legal ramifications.

It is noteworthy that most couples consider it likely they will seek outside information to help them make the decision about what to do with their excess stored embryos. Indeed, only 10% of couples indicated they were comfortable making the decision alone. Moreover, in addition to formal counselling, couples are likely to seek information and advice from a range of different sources, including fertility nurses, scientific staff from within fertility centres, gynaecologists and general practitioners, as well as family members and ministers of religion. The need for educational programs on issues relating to embryo donation to another couple has been raised previously.[7] Our findings support this view, and suggest that programs should be extended to encompass all potential donation options, including medical research.

COMPETING INTERESTS

None identified.

REFERENCES

1. Trounson A, Mohr L. Human pregnancy following cryopreservation, thawing and transfer of an eight cell embryo. *Nature* 1983; 305: 707-709.
2. Dean JH, Sullivan EA. Assisted conception Australia and New Zealand 2000 and 2001. Sydney: Australian Institute of Health and Welfare National Perinatal Statistics Unit, 2003: 7.
3. Hoffman DI, Zellman GL, Fair CC, et al. Cryopreserved embryos in the United States and their availability for research. *Fertil Steril* 2003; 79: 1063-1069.
4. Lornage J, Chorier H, Boulieu D, et al. Six year follow-up of cryopreserved human embryos. *Hum Reprod* 1995; 10: 2610-2616.
5. Hounshell CV, Chetkowski RJ. Donation of frozen embryos after in vitro fertilization is uncommon. *Fertil Steril* 1996; 66: 837-838.
6. Darlington N, Matson P. The fate of cryopreserved human embryos approaching their legal storage limit within a West Australian in-vitro fertilization clinic. *Hum Reprod* 1999; 14: 2343-2344.
7. Kovacs GT, Breheny SA, Dear MJ. Embryo donation at an Australian university in-vitro fertilization clinic: issues and outcomes. *Med J Aust* 2003; 178: 127-129.
8. Reproductive Technology Accreditation Committee. Code of practice for centres using assisted reproductive technology. Sydney: Fertility Society of Australia, 2002: 34.
9. McMahon CA, Gibson FL, Leslie GI, et al. Embryo donation for medical research: attitudes and concerns of potential donors. *Hum Reprod* 2003; 18: 871-877.
10. Moutel G, Gregg E, Meniguad JP, Herve C. Developments in the storage of embryos in France and the limitations of the laws of bioethics. Analysis of procedures in 17 storage centres and the destiny of stored embryos. *Med Law* 2002; 21: 587-604.
11. Bjuresten K, Hovatta O. Donation of embryos for stem cell research — how many couples consent? *Hum Reprod* 2003; 18: 1353-1355.
12. National Health and Medical Research Council. Embryo research. Available at: www.nhmrc.gov.au/embryo/index.htm (accessed Apr 2004).
13. Kovacs GT, Morgan G, Wood C, et al. Community attitudes to assisted reproductive technology: a 20-year trend. *Med J Aust* 2003; 179: 536-538.
14. Soderstrom-Antilla V, Foudila T, Leslie G, et al. Embryo donation: outcome and attitudes among embryo donors and recipients. *Hum Reprod* 2001; 16: 1120-1128.

(Received 23 Dec 2003, accepted 1 Apr 2004) ❑